DOCUMENT RESUME

ED 287 264 EC 200 572

AUTHOR	Lipsky, Dorothy Kerzner, Ed.; And Others
TITLE	Family Supports for Families with a Disabled Member. Monograph No. 39.
INSTITUTION	World Rehabilitation Fund, Inc., New York, NY.
REPORT NO	ISBN-939986-52-3
PUB DATE	87
NOTE	76p.; Prepared by the International Exchange of Information in Rehabilitation.
AVAILABLE FROM	World Rehabilitation Fund, International Exchange of Experts and Information in Rehabilitation, 400 East 34th St., New York, NY 10016 ($4.00).
PUB TYPE	Guides - Non-Classroom Use (055) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Cultural Influences; Delivery Systems; *Disabilities; *Family Influence; Foreign Countries; Minority Groups; *Rehabilitation; *Social Support Groups
IDENTIFIERS	Canada; England; Israel; Sweden

ABSTRACT

Five articles address issues in family support systems for persons with disabilities. Peter Mittler, Hellie Mittler and Helen McConachie present a set of general principles designed to encourage the development of genuine partnerships between professionals and parents in "Working Together: Guidelines for Partnership between Professionals and Parents of Children and Young People with Disabilities." In "Cultural and Ethnic Aspects of Family Support Services for Parents of a Child with a Disability," Victor Florian analyzes three ethnic minority groups in the United States and draws implications for service delivery. Annat Kalir briefly describes "A Mother-Child Program in Israel." Inger Claesson Wastberg recounts the work in Sweden to build family support as a means to avoid institutionalization of children in "Family Support in Sweden." Bruce E. Kappel concludes the monograph by identifying four approaches to enhancing parental power in "Family Support in Canada--Trends and Challenges." (CL)

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39 FAMILY SUPPORTS FOR FAMILIES WITH A DISABLED MEMBER

Edited by Dorothy Kerzner Lipsky

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MONOGRAPH NUMBER THIRTY NINE

FAMILY SUPPORTS FOR FAMILIES WITH A DISABLED MEMBER

Edited by Dorothy Kerzner Lipsky, Phd
with an Introduction by Dr. Lipsky

International Exchange of Experts and Information in Rehabilitation
World Rehabilitation Fund, Inc.
400 East 34th Street
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ISBN #939986-52-3

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Preface and Acknowledgements

"Family Supports" has been one of the priority topics considered in the International Exchange of Experts and Information in Rehabilitation over the past two years.

Dorothy Kerzner Lipsky, the editor of this monograph, was awarded a fellowship in 1985 to study Family Supports in Israel; in 1986 Ann and H. Rutherford Turnbull carried out parallel fellowship studies in parts of South America. They looked at the relationship of ethnicity and Latin American culture to transition from childhood to adulthood of children who are mentally retarded and how culture influences families' planning for transition.

A 1987 fellowship study-visit carried out by Shirley Cohen and Rachel Warren focussed on child abuse and family support systems in England (with of course an emphasis on families with a disabled child.)

The IEEIR fellowship program produces about twelve fellowship reports a year prepared by U.S. experts who have been awarded fellowships to study overseas. They are asked to report on their experiences in terms that could affect policy and practice here in the U.S.

For the monograph series foreign authors are selected based on recommendations that come to us from a variety of sources.

We wish to acknowledge the participation in this monograph of the several authors and thank them for sharing their ideas with us. We wish to express our appreciation to Dorothy Kerzner Lipsky for the significant role she played in editing this monograph.

The National Institute of Disability and Rehabilitation Research is to be acknowledged for its support of these international exchange of knowledge efforts through its grant to the World Rehabilitation Fund.

We hope you the reader will find this particular sharing of ideas from England, Canada, Sweden and Israel an interesting one.

Diane E. Woods
Project Director
International Exchange of Experts
and Information in Rehabilitation

INTRODUCTION AND OVERVIEW
Dorothy Kerzner Lipsky

Family support services are increasingly a part of the systems to serve persons with disabilities. Their development starts, of course, with the recognition that the consequences of disability affect both the individual and others in the family. The issue then becomes the nature of that support, affected both by the characteristics of the family and its dynamics and the individual who is disabled and his/her characteristics.

The articles in this monograph address several aspects of these issues: (1) the need to understand the cultural characteristics of families and how they mediate the reaction to the situation; (2) the bases of family-professional relationships, especially as it involves young children; and (3) the characteristics of family support systems, especially as they may serve to empower individuals and families. Before turning to a brief summary of the articles, let me suggest some contextual issues. First, the shape of what is meant by "family support" varies widely among states in the United States and other countries. However, the rationale behind the development of family support systems is similar and stems from the belief that "An intact family offers stability, consistency, and close relationships which cannot be duplicated. ... Like other people, the quality of life for developmentally disabled people is at its best when they can live in their home."* Recognition that governments may have endorsed family support services as cost saving devices does not gainsay the potential benefits for the individuals involved nor deny their need.

We must be careful, however, to avoid the exclusionary consequence of concepts expressed in terms such as "intact family," especially given the increasing prevalence of single-parent families.

The range of family support services may be categorized in ten broad groupings.

- *Outreach*, including information and referral, prevention and public information;

Family Support Services: Expanding Alternatives for Families With Developmentally Disabled Individuals (Albany, NY: Office of Mental Rehabilitation and Developmental Disabilities, 1985), p.1.

- *Family member/care giver training*, including training of primary family care givers, specialized behavioral services, sibling services;
- *Counseling*, including genetic counseling, personal adjustment to a disabling condition, and counseling dealing with the dynamics of family relationships;
- *Respite*, including day or overnight respite, homemaker service, family care, community residencies, volunteer respite, drop-in centers, sitter companions, host families, guest homes, and parent exchange networks;
- *Transportation;*
- *Special assistance services*, including home habilitation, home care, and nutritional services;
- *Financial assistance*;
- *Housing assistance services*, including adaptive equipment and home modification;
- *Recreation*; and
- *Crisis Intervention Services.**

No state in the United States provides all or even most of these services.** What I intend by this list, which is not exhaustive of all components of a comprehensive family support system, is to suggest the range of issues which need to be considered. In doing so, there are at least five sets of factors to consider in shaping family support systems:

1. the dangers in most professional formulations of the consequences of disability for a family, which emphasize pathology and ascribe deviancy, necessitating professional treatment, to any family response;***

2. the potential that in understanding the family consequences (that is the impact upon the non-disabled members), the special and unique needs of the individual with the disability will be downplayed if not ignored;

3. the need to recognize that families differ, in composition, needs, cultural heritage, life stage, each of which affect their understanding of and reaction to disability;

4. the need to address a set of gender issues—both the special issues involved for women with disabilities and the special care giver responsibilities which many cultures assign to women; and

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*Dorothy Kerzner Lipsky, *Family Supports in Rehabilitation in Israel*. (New York: World Rehabilitation Fund, 1985), p. 51.

**The most comprehensive report of family support services in the United States is to be found in J.M. Agosta and V.J. Bradley (Eds.) *Family Care for Persons with Developmental Disabilities: A Growing Commitment* (Boston, MA.: Human Services Research Institute, 1985).

***Dorothy Kerzner Lipsky, "A Parental Perspective on Stress and Coping," *American Journal of Orthopsychiatry*, 55,4 (October, 1985), 614-617.

5. the uniqiue feature that unlike traditional minority families seeking to buffer and protect each other from the hostility of the larger society, the child with a disability is (most often) a member of a family which does not share in the experience (or culture) of disability. Thus, in addition to the strengthening which comes from a strong system of family supports, children with disabilities need opportunities to be with and learn from other persons with disabilities.

This monograph includes three major articles, and two shorter pieces. While the authors of the first three are from different countries—Israel, Great Britain, and Canada—their pieces are presented more to offer varying facets of understanding families' needs and support system characteristics. The other two pieces, one from Sweden and the other from Israel, illustrate the experiences in those countries.

Peter Mittler, Helle Mittler, and Helen McConachie take a comprehensive view, building upon their experience in the United Kingdom to present a set of general principles designed to encourage the development of genuine partnerships between professionals and parents on behalf of children with disabilities. In doing so, they suggest seven reasons for such partnerships.

1. Growth and learning in children can only be understood in relation to the various environments in which the child is living.

2. Parents and professionals concerned with the development of children with disabilities share a number of basic goals.

3. Parents and the extended family are the adults who are normally most accessible to the child.

4. Parents and professionals each have essential information which needs to be shared among all who are concerned with the child's development.

5. Knowledge and experience of bringing up non-handicapped children and ordinary parental intuition, while undoubtedly valuable, are not necessarily enough to aid the development of a child with a disability.

6. The age of the handicapped child is not always an adequate guide for the parent.

7. In a number of countries, parents' rights to be involved in discussion and decision making concerning their child are now incorporated in law.

Given these reasons for partnership, they turn first to examining the needs and strengths of families, noting that families differ, in terms of the nature and severity of the child's disability, the stresses on the family and their own resources for coping, the attitudes of the society they live in toward disability, and the nature of the services they receive. And in looking at

families, they are careful to note both the variety of family structures and the differing needs of family members—mothers, fathers, siblings, and grandparents.

In characterizing what they mean by partnership, Mittler et al. emphasize that real collaboration rests on the basic recognition that both sides have areas of knowledge and skill which can contribute to the joint task of improved programs and services for the benefit of the child. In doing so, there is not an identity of roles, but rather complementarity. The partnership concept put forward is built on professional accountability to parents. It includes mutual respect, sharing in a common purpose, joint decision making, sharing feelings, and flexibility in approach in dealing with each other.

In the article from Israel Victor Florian reminds us that in the new focus on the family framework in developing more effective services, there is a danger that we will fail to recognize the variety of families, both as to composition and (his focus) different ethnic and cultural forms. He frames his argument for such understanding in the context of the literature concerning family reaction to the birth of a child with a disability. His analysis emphasizes more of the uniquely negative consequences than do the authors of the previous piece but is in consonance with them as to: (1) parents' needs for accurate information; (2) the differing needs as children grow older; and (3) the substantial demands on a family's energy supply, exacerbated by the fragmentation of services and multiplied when external stresses, such as inflation, unemployment, and lack of services, press in on the family.

Florian's article emphasizes that while cultures vary as to their attitudes toward a child with a disability—some cherishing, other ostrasizing, still others overprotecting and infantalizing—in every case, at least to some extent, the families of such children will be socially stigmatized. While he asserts the universality of such attitudes, he says there will be variability as to how the stigmatization is experienced by the families depending upon three cultural dimensions: 1) traditional versus modern family systems, 2) homogenous versus heterogenous backgrounds, and 3) shame versus guilt oriented cultures. (In a shame oriented culture, conditions such as a physical disability will be hidden, while in a guilt oriented society, reactions may involve ongoing self-blame and a strong sense of personal responsibility for the condition.)

Using these three dimensions, plus recognition that when the family is part of a "minority" group in the society they evoke yet another set of assumptions, he analyzes the reactions of U.S. groups, Pacific/Asian families, Black Americans, Mexican Americans, and those of Arab and Jewish communities in Israel. There is a nice distinction between Jews of western origin and those of Oriental background, whose reactions are more like those of the Arabs. One wonders, however, if Jews and Arabs do receive the same services; one would think his point as to the differential pattern of services

and the roles and attitudes of majority culture service providers experienced by Black families in the U.S. would apply, as well, to Arab families in Israel.

The Bruce Kappel article from Canada combines themes of both previous pieces, noting that the work of family support involves a basic shift in service focus and design, indeed in power between professionals and families. From a situation where, in his words, "families were denied support, yet encouraged to place their children in services which received support," the new arrangements emphasize the empowerment of families.

Interestingly, the two provinces, New Brunswick and Newfoundland-Labrador, which have done the most to support families with children at risk of institutionalization and to support the return of children from institutions, are among Canada's most resource poor. In supporting the return of children, services include in-home support, respite services, child and behavior management programs, a special child welfare allowance; on the success side, there are no children in institutions in New Brunswick. In supporting at risk children, services include interdisciplinary assessment and care planning, service coordination, respite care, family support, rehabilitation services, and early intervention. And Newfoundland-Labrador's only children's institution has been recently closed.

The Kappel article identifies four aspects of enhancing and supporting parental power, emerging in the work in these two provinces and elsewhere in Canada, particularly in efforts in Vancouver, British Columbia. They include enhancing:

1. decision making power, as to what their children need;
2. spending power, in the form of funds which are at the disposal of families;
3. knowledge power, with professionals teaching skills to parents; and
4. mutual power, with parents joining together.

In an interesting symbiosis, he points to the joining together with non-handicapped people as both means toward the achievement of integration and the goal to be sought.

Inger Wästberg, in a brief excerpt, describes the work in Sweden to build family support as a means to avoid institutionalization of children. The success of these efforts is seen in the reduction, from the mid-1970's to 1986, in the institutionalized population of children with mental retardation from 2,500 to 400. And of these, fewer than twenty were under the age of seven. Support to families includes a multidisciplinary team in every area, out-of-the-home respite care with a family entitlement of a week per month, comprehensive day care and school programs which incorporate the services of a home teacher. While clearly a success in terms of deinstitutionalization, Wästberg points out that stress on the family, particularly mothers, remains considerable.

In Israel, in addition to a comprehensive professional system of Mother and Child Health (MCH), Anat Kalir describes a payment system which provides funds directly to families below a certain income level to cover the extra expenses of a child with a handicap remaining at home. Such a cash payment system reinforces efforts in the U.S., where disability rights advocates have favored voucher payments directly to consumers rather than to service providers. Unlike Sweden, however, which focusses particularly on families with the youngest children, the program in Israel does not apply to children from birth to three years of age, and as Kalir points out, its focus is less on developing the child's skills but rather on identification and compensating for disabilities.

We have then in these five pieces both guidance and reports of experience toward the development of more effective systems of family support. At this point in the development of such systems, it would be premature to offer a template. It may be appropriate, however, to suggest that whatever the particulars, necessarily adapted to a given situation, among the characteristics of an effective family support system would be:

- *early initiation*, that is the system reaches out to the family at the beginning of the family's involvement;
- *integrated services*, while families will begin with one or another need, most often there will be a variety of needs, generally meetable by differing agencies. Whatever the institutional reasons for this, from the family's perspective receipt of the array of needed services should not be a function of agency territorial lines or eligibility criteria or service plans or professional prerogatives;
- a concomitant of this is *universal access*, that is whenever a family enters the system, all parts should be available to them;
- while the totality of services may run a wide range, for any individual family it is its *unique set of needs* that must be addressed—in effect selection from a *cafeteria of services*;
- while we have talked of a family's needs, in fact the members of the family have unique needs, both the disabled person and the other individual members, so that the services must be *individualized*;
- while supports are designed to respond to needs, they should be designed to *build on and bolster strengths* and not focus on deficits;
- the shared experiences of families with a disabled member offer the basis for *mutual support* among such families;

- paramount recognition needs to be given to the family's capacity, including the ability to determine their own needs. Thus, in the determination of needs and the ways to meet them, the wishes of the family and of its members should be given priority.

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WORKING TOGETHER: GUIDELINES FOR PARTNERSHIP BETWEEN PROFESSIONALS AND PARENTS OF CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

Peter Mittler, Hellie Mittler, Helen McConachie

Commissioned by UNESCO from The International League of Societies for Persons with Mental Handicap (Brussels, Belgium)

Introduction: A Justification for Partnership

The growth of better working relationships between professionals and parents of children with disabilities constitutes one of the most important developments in the field of special education and rehabilitation services. But despite encouraging evidence of the benefits of such collaboration to children, as well as to families and to professionals, progress has been slow and uneven. This unevenness is not directly related to the degree to which services are well developed or well resourced. Some of the most interesting examples of parent-professional relationships have come from poorer countries with only limited resources. Countries with advanced and well established educational systems have often found it difficult to break with traditional practices which create a distance between home and school.

We will use the term 'professional' to include a wide range of people. They include teachers working with children and young people of all ages, whether attending school or not; health professionals working in peoples' homes as well as in health centres and hospitals; staff concerned with helping adolescents and young adults to live, learn and work in their local community, as well as social workers and staff of voluntary agencies. We therefore need to think of the goal of partnership as it relates to all those people with whom the child and the family come into some form of working relationship.

We seek to promote good working relationships between parents and professionals as a first step in the building of partnership. We see true partnership as the ultimate goal, and good working relationships and collaboration between parents and professionals as essential stepping stones towards this goal. A commitment to partnership implies a sharing of knowledge, skills and experiences in meeting the individual needs of children as well as the individual needs of families. It assumes that children will learn and develop better if parents and professionals are working together than if either is working in isolation.

Reasons for Partnership

There are many facts and arguments to support the development of closer working relationships between parents and professionals. We summarize some of the more important considerations below:

1. Growth and learning in children can only be understood in relation to the various environments in which the child is living. These include the family, peers, schools, the local community and the wider society. The study of child development calls for an examination of ways in which the child interacts with, affects and learns from these environmental influences. We can neither study nor teach the child in isolation.

2. Parents and professionals concerned with the development of children with disabilities share a number of basic goals—e.g. teaching the child self-care and social independence, including feeding, dressing and toileting. They are both concerned with helping the child to learn to communicate and to understand others and finally to adapt to the expectations of the local community.

3. Parents and the extended family are the adults who are normally most accessible to the child. They are therefore the most easily available people to help a child with a disability. Professional expertise—which is more expensive and in many countries less available—is therefore most effective if it is used to help as many parents as possible to help their own children. Some parents can then share their skills with other parents.

4. Parents and professionals each have essential information which needs to be shared among all who are concerned with the child's development. Parents know their own child best, as well as the environments in which the child is growing up. Professionals have developed certain specific strategies and methods to help children to acquire the skills they need. The greater the child's difficulties, the greater is the need for parents and professionals to adopt a reasonably consistent approach to achieve particular goals. Such methods need to be discussed and agreed upon, so that, at the very least, each is familiar with the approach taken by the other.

5. Knowledge and experience of bringing up non-handicapped children and ordinary parental intuition, while undoubtedly valuable, are not necessarily enough to aid the development of a child with a disability. Nor is it enough to prepare parents for some of the specific difficulties which they may experience in raising children whose development is not proceeding normally.

6. The age of the handicapped child is not always an adequate guide for the parent. Parents may become discouraged by what may appear to be a general lack of progress. They may be puzzled by the child's uneven development—particularly slow in some areas, relatively normal in others. They

may be confused about the kinds of demands and expectations which are appropriate for their child, how they can extend the child's range of experience and how they can both protect the child and promote development. It is in areas such as these that the wider experience and knowledge of the professional can be particularly helpful in preventing difficulties and problems which could, unwittingly, add to or complicate the primary impairment. The professional is in turn dependent on the parents' observations, and on the day to day adaptation and implementation of the advice which they offer.

7. In a number of countries, parents' rights to be involved in discussion and decision making concerning their child are now incorporated in law. Such rights include the right to information, access to records, participation in assessment and in the development of plans to meet the child's needs, as well as in regular reviews of progress. Although only a few countries have so far adopted such laws, the principles underlying collaboration between parents and professionals are increasingly accepted as good practice in many countries.

Conclusions

Despite enormous differences in progress and practice throughout the world, we believe that the needs of children and families have enough in common to justify this attempt to develop certain general principles, as well as more specific guidelines for action. These might form a starting point for discussion at local level and will need to be adapted to local circumstances.

Most of the examples of partnership between parents and professionals which have come to our attention are reported from special schools. Will it be possible to develop the same kind of partnership with teachers in ordinary schools? This is one of the major challenges for the future.

The Needs and Strengths of Families

Families of disabled children vary as much in their behaviours and attitudes as any other families. The fact that they have a disabled child does not make them any more homogenous as a group than they were before the birth of the child. It is the task of professionals not only to recognise the distinctive and unique characteristics of each family, but also to approach the task of building a working relationship with the family in flexible and individually appropriate ways.

The needs of families will differ in relation to:

—the nature and severity of the child's disability;

—the stresses on the family and their own resources for coping;

—the attitudes of the society they live in toward disability;

—the nature of the services they receive.

However, before discussing families' special needs, and reactions to disability, it is necessary first to stress the essential similarity in many respects between families of disabled children and families of non-disabled children. For example, problems of poverty and poor housing may be more acutely stressful for families than the child's disability. Research on the family life of disabled children in developed countries has concluded that, in general, families meet the day to day problems created by the child's disability in ways that are fairly typical of the behaviour of any other family (e.g. Hewett, 1970). Most parents of disabled children have also had other normal children, and therefore have considerable experience not only of child-rearing, but also of helping their children to achieve independence as they grow up. It therefore makes sense, in creating services, to harness the experience and expertise of parents in bringing up their own children, and in knowing the needs and strengths of their disabled children.

To stress the essential individuality and normality of families is not to deny the range and severity of the problems they face. The aim is rather to challenge the assumptions and stereotypes which are so often used by professionals about the underlying social pathologies to be found in the families. What is at stake here is the danger that negative attitudes in professionals will result in a lack of appropriate action in response to families' needs. For example, parents seeking help at an early stage have frequently reported being labelled 'overanxious' and denied credit for close observation of their child. With the current emphasis on 'care in the community,' families seeking residential care for their disabled member may be investigated for 'guilt' and 'rejection.' On the other hand, if respite care services are available, parents who do not wish to use them may be labelled 'overprotective.' So the behaviour of families may be interpreted as abnormal whatever they do. Such negative stereotyped judgements are a poor basis for collaboration.

Family reactions

Even in countries where many surveys have been done of the needs and feelings of families of disabled children, services may still be set up in ways which reflect the needs and priorities of professionals rather than of families. Still more information is needed as to how the family as a whole may react to a child's disability, and what needs different family members may have.

A wide range of parental reactions have been documented to the discovery of the child's disability. Parents' feelings may seem both protective and rejecting in response to the abnormality. They may feel inadequacy as parents, and fear for the future. They may experience feelings of bereavement and embarrassment (Cunningham and Davis, 1985). Less is known about whether these reactions are also characteristic of other members of the family such as sisters, brothers or grandparents, and how the feelings of one

member of the family affect another member, spouse to spouse, parent to child, etc. For example some fathers may seem to shut themselves off, work long hours, and not talk about their feelings; this will in turn reduce their capacity to support the mother emotionally. Family members' strong and long-lasting feelings need to be accepted by professionals, and seen as a natural reaction. Periods of careful listening are an essential element in practical partnership.

A pressing need for many families is for information. Research suggests that for parents (though perhaps not for siblings) the need to understand the nature of the child's disability more fully is a priority. They also need to know what to expect in the future not only in terms of the child's development but also in relation to whatever community services, aids and grants may be available. Finally, parents need to know what they can do to help the child. The ways in which such information is made available need careful consideration and ingenuity—for example, leaflets with explanatory illustrations, radio programmes, etc.

The task of bringing up a disabled child is a complex and tiring one. Children may be a drain on the family finances, through needing special equipment, replacement of bedding if the child is incontinent, replacement of clothing worn out quickly if the child is crawling, difficulty in travelling, and attendance at hospital appointments. Also family finances may be affected through the mother not having paid work, wanting to stay with the child or not being able to find someone who will do so while they work. The everyday tasks of child-care are greatly increased, as many children need constant supervision in order to keep them occupied and out of danger, and occupied in play. Feeding, toileting, washing may involve parents' time and attention for much longer than in the case of non-disabled children. Repeatedly having to lift a physically disabled child will be exhausting. Many disabled children have disturbed sleep patterns, which will further drain parents' energy.

So the services which parents may much appreciate are those which provide someone to share the burden of caring—babysitting while the parent goes out for a while, helping during school holidays, befriending the child, etc. In countries which have a choice of services, playgroups, toy libraries, transport services and financial aid are all important provisions in supporting parents in caring for and enjoying their child.

Families need information and opportunities for discussion as an essential foundation for helping them to make rational and informed choices about ways in which they can make best use of existing services, or press for services that are not available or are being employed in ways that do not meet their needs. Parental feelings of fear and inadequacy are a natural reaction to disability in a child, but for such reactions to be prolonged may be a direct reflection of lack of appropriate help from professionals.

Coping

Families and family members will also differ in the extent to which they have resources for coping with the stresses and strains resulting from the child's disability:

—physical health and emotional stability;

—past experience in problem-solving, such as seeking out information and support;

—the helpfulness and size of their social network;

—financial resources;

—their values and beliefs.

Thus, in setting up a working relationship, professionals have to be aware of parents as complex individuals with their own resources and strengths, as well as having areas in which they need support. It may be as important for professionals to enable mothers to look after their own physical health, as to consider the child directly. It may be as important to facilitate parents of disabled children meeting each other for mutual support, as to focus direct services on the disabled child.

Parents' perceptions of society's view of the disabled child are likely to have a strong influence on their feelings about their own capacity to love and care for the child in the family. There have been few cross-cultural studies of public attitudes to disability, and much of what is 'known' is anecdotal. Such surveys as there are demonstrate the dangers of generalisation—community attitudes vary not only across societies but also within them, even between adjacent neighbourhoods. It is also the case that community attitudes reflect both positive and negative impulses toward disability (Mittler and Serpell, 1985). It will be an important aspect of partnership with parents, for professionals to help parents to gain positive support from the community, for example, through community leaders, or women's organisations, giving members accurate information about the disabled child and encouraging the child's inclusion in commmunity activities.

Parents' attitudes and beliefs, as a reflection of society's attitudes, may need to be expressed in discussion in order to examine where they may conflict with professionals' assumptions. For example, in order for parents to work with professionals in promoting their child's development, there will need to be acceptance of the idea that intervention can be effective. Some parents of intellectually disabled children may not believe that the child can be helped to progress. A second example is where professionals suggest that parents spend time in teaching their children new skills in regular, structured sessions. Yet it may be culturally unfamiliar, or felt completely inappropriate by parents to spend regular periods in intensive play with their children, let

alone such activities being difficult to arrange when parents have to work long hard hours. The culture of the society may instead emphasise children's independence from their parents in terms of daily activity. Professionals may then need to consider ways of involving other children in aiding the disabled child to progress, or developing strategies with the parents whereby the time they already spend with the child (e.g. feeding, dressing) is exploited in terms of promoting the child's development of skills toward independence. Models and assumptions about services which are seen as useful in one country will not be appropriate for implementation unrevised in other settings.

Family members

(1) *Unsupported mothers.*

So far we have used the term 'parents.' However, many mothers are in fact looking after disabled children on their own, with little help or support from other family members or from the surrounding community. Also many families are headed by only one parent, usually the mother. Unsupported mothers have special problems. Even in the few countries where special financial grants are available to parents of disabled children, these are rarely adequate to provide help in the day-to-day task of looking after a home and caring for and working with a disabled child. Many mothers have to, or choose to have paid work, just as mothers of non-disabled children do. Professionals need to be fully aware of the pressure on mothers, and not create additional pressures through the programmes they suggest. A range of flexible services for mothers to choose from would be the idea.

(2) *Fathers.*

Contacts with professionals have often excluded fathers in the past. Where fathers are for any reason not available (e.g. work commitments), it may be very difficult for mothers to pass on the information and advice they have received from professionals or other parents. Thus the effect of service provision may be in some ways to divide the child's parents, to make fathers feel incompetent in relating to their disabled child, and to lead to inconsistent handling. In most societies, men take a limited part in the day-to-day tasks of ordinary child-rearing. To what extent should professionals try to expect more of fathers, since special children create extra burdens and may call for special measures? What extra information and opportunities would fathers appreciate and respond to? These are questions which need raising in discussion between parents and professionals, in order to meet parents' needs flexibly.

(3) *Sisters and brothers.*

These are perhaps also questions to ask in relation to siblings. It used to be generally assumed that brothers and sisters would inevitably suffer from the presence of a disabled child in the family; indeed, it is with their needs in mind that physicians have often prescribed institutional care outside the

family. But there is very little evidence which would support such an over-simplified view. Of course, there are individual families where the siblings have undoubtedly suffered, and some consistent evidence that older sisters may have too much expected of them in terms of helping to care for the disabled child. But in general the picture from a number of studies is not of widespread adverse effects.

On the other hand, we have little information on the ways in which siblings can contribute positively to systematic work in partnership with parents and with professionals. Here again it is important to respect local social and cultural traditions and the wishes of parents and siblings themselves. In many countries, siblings play a large part in caring for small children. On the other hand, many parents do not wish to involve the disabled child's siblings in detailed programmes of stimulation and training or in taking the child with a disability around with them, on the grounds that they should be allowed to get on with their own lives and that the presence of the disabled child imposes adjustment problems enough on siblings without demanding additional efforts from them. However, much can be gained by sharing feelings, information and work, strengthening family bonds; brothers and sisters too should be helped to choose whether and to what extent to participate.

(4) *Grandparents.*

We have almost no research information about the reactions of grandparents (and other extended family members) to disability in a child, and about the role they can play in helping the child and parents. Certainly grandparents do have strong reactions to their grandchildren, and can be a source either of great support or of tension to parents. Research does suggest that even in developed countries in urban areas, contacts with grandparents are frequent in a high proportion of families. Grandparents' role often seems to be one of providing general support: financial help, making special clothes or equipment, being there in a crisis. Professionals can in turn sensitively support this important role, in their attempt to build a broad-based and flexible working relationship with families.

Thus no one approach can ensure success in working with all families of disabled children, because each family is unique. Different family members have different reactions to the child, and different strengths in coping and adjusting. Each family and extended family has different ways of communicating with each other, and in asking for and giving help and support. However, the next chapter suggests some principles on which successful collaborative working relationships between families and professionals may be based.

The Essence of Partnership

We have stated in the introduction that we see partnership as the essential principle on which to base the development of working relationships between professionals and parents of disabled children. In this chapter we attempt to define what we mean by partnership.

The partnership we have in mind implies professional accountability to parents. It also implies equality between parents and professionals. Partnership can take many forms but all must rest on basic recognition that each side has areas of knowledge and skill to contribute to the joint task of working together for the benefit of the child. As a starting point, professionals might think of parents as active 'consumers' of services, and not as 'patients' (an essentially passive label).

Partnership implies shared activities and decisions. But there cannot be a prescription for particular joint activities which would represent 'partnership' in action. There will be an infinite range of particular forms of working relationship depending on the context within which the work is undertaken and how the family lives. Working together encompasses a wide range of activities, from exchanging basic information about the child's health, right up to parents being very closely involved in the child's education and contributing to decisions about policy and allocation of resources.

Ultimately services to disabled children are a matter of rights, including parents' rights, and thus of professional duties. It is part of the professionals' responsibility and task to make the relationship work as a partnership and be of benefit to the child. Professionals need to strike a balance between offering to help parents to augment their skills in specialised ways (e.g. learning how to do physical exercises, prepare special diets, train their child toward independent mobility, etc.) while at the same time supporting their strengths and sense of identity as parents. Children have complex needs in growing up. Disabled children need from their parents not only encouragement to try harder and teaching to achieve more, but also their parents' unconditional love and acceptance. This balance can only be achieved by consulting parents about their own needs and preferences.

How can professionals assess the nature of the services they are offering against the guiding principle of partnership? There are several key features embodied in the concept of partnership.

(1) *Mutual respect*

Perhaps the key element in the development and success of partnership is mutual respect of the different qualities and skills which both sides bring to the relationship.

Parents and professionals both have a deep interest and concern for the child, but the parent is more deeply involved. Most parents have a life-long commitment to the child and their responsibility lasts for 24 hours a day,

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during holidays and sickness. Their feeling of their own capability and work as parents may be intimately tied up with their child's development. Their detailed knowledge of the child derives from this day-to-day life-long love and care.

The professional has, on the whole, a more finite commitment. The focus of a professional's work is usually specialised in some way—concerned with education, health, hearing and language, mobility, vocational training, and so on. Also the professional may choose to change jobs, or work with another group of children.

Nevertheless, the roles of parent and professional in the field of disability are more than usually interactive and complementary. The warm and affectionate care of the parent and the physical help a parent offers will need also to be given by the professional. Parents have knowledge, skills and experience in bringing up their child which they can offer to the professional and to other parents. Similarly, the knowledge and experience which professionals have accumulated in working with disabled children need to be passed on as skills to parents, to enable them to minimise the child's handicap by continuing teaching at home.

Mutual respect does not mean professionals standing back and saying "parents are the only true experts." Parents look for active, purposeful help from professionals in bringing up their child, but in a way which is fully integrated with their own patterns and priorities for the child.

(2) *Sharing—a common purpose*

Partnership involves a dialogue and an agreement of common purpose. It is perhaps surprising how rarely parents have been asked for their opinions—for instance, about what they feel their child should be learning. Professionals can usefully ask parents actively and directly about their ideas, and about their preferences for collaboration. They need to do so at regular intervals as circumstances, needs and priorities change.

Joint assessment of the child should be a process which operates right from the start. Parents have a wealth of information about their child, even if they do not have a systematic way of reporting it. They also have a wealth of experience, for example, in interpreting the ambiguous cues which a blind child may give as to whether he or she is listening, or the jerky, misdirected movements of a child with cerebral palsy. They know the child's likes and dislikes. Also they have over time built up a way of interacting with and managing the child which, to a greater or lesser extent, is comfortable for them. All of this information is vital to the professional in making a full assessment of the child. Likewise, the process of assessment is an important and revealing experience for parents. Noting all the things that the child can do may 'open parents' eyes' to a new view of the child, where before they

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may have been concentrating on what the child cannot do. And it can help bring home realities to parents who have not allowed themselves to see the child's difficulties clearly before.

It is from this basis of asking and listening and working together that parents and professionals can develop a mutual understanding and a common purpose. Parents can then find out why suggested activities may be important for a child, and have an informed basis from which they themselves can make suggestions on how the activities can best be carried out. It is important for professionals to encourage parents to ask "Why?".

(3) *Sharing—making joint decisions*

The making of decisions is the area from which parents of children with disabilities are most often left out by professionals. They have been expected to fall in with professionals' opinions and planned programmes, or have been given the opportunity only to agree or disagree with decisions already taken. Professionals may be nervous of involving parents at this level, fearing they might take over. This defensiveness is clearly observed by parents. "Professionals simply can't resist taking over", was how one group of parents from France put it to us. But joint decision-making, in the best interests of child, parent and professional, is what is implied by partnership.

Parents in some countries have increasingly asserted their wish to be consulted. In the United States of America, for example, the 1975 Education for All Handicapped Children Act ensured that parents are equal members with professionals of the committee which decides on the individual educational programme for the child. Many home-visiting educational programmes (see next chapter) have parents on their management committee, ensuring that the programme continues to be responsive to parents' differing needs and situations. Parents' organisations as well as organisations of disabled people are crucial members of the joint consultative committees which advise many governments on policy.

At the individual level, professionals need to make joint decisions with parents about teaching programmes. These may be carried out by one or the other, not necessarily together. But for the maximum appropriateness and functional usefulness, teaching goals need to be decided jointly. For example, if a teacher or therapist decides that a child needs to learn to sit in a particular beneficial way, there also needs to be a joint decision with the parent about whether or how often to enforce this when the child is with grandparents, or playing with other children.

It is also important for professionals and parents to decide on a method for continuing communication between them, whether this is through written notes, home visits, parents' group at school, telephone, etc. Regular continuing communication is essential to partnership, and as children progress or problems are encountered, decisions will continue to need updating.

(4) *Sharing feelings*

Partnership involves sharing, not only of skills and information, but also of feelings. It may be vital for parents who sense rejection of their child and of themselves because of the child's disability to experience a professional really enjoying their child, and showing pleasure in what the child does.

Traditionally, parents and professionals are wary of one another. They come together hindered by preconceived assumptions and ideas. If parents expect teachers to be rather remote, superior figures, it will come as something of a shock if they realise that teachers of disabled children may, like themselves, often be floundering and overwhelmed. Also then parents will be unprepared for teachers who offer them opportunities for day-to-day participation in assessing the child's needs and in implementing collaborative teaching. Professionals, as much as parents, will lack confidence in how to approach the other; professionals rarely have preparation or training in ways of relating to parents.

Professionals can begin to meet parents on a personal level by being open about their own feelings. Sharing their initial reactions to disability and early difficulties and failures may make parents more comfortable in expressing their own doubts and worries. Similarly, professionals and parents can help each other through periods when little progress is being made and it is only too easy to be discouraged. Sharing of feelings, with the knowledge that progress often comes in spurts after a consolidation period, can bring comfort to both.

The sharing of positive feelings may be even more important, feelings of warmth toward the child, and feelings of satisfaction at achievement. Success is very precious when much effort has gone into helping a disabled child take even a small step forward in development.

Such a two-way process of support between parent and professional is of inestimable value to the child, but it is only possible on the basis of a genuine flow of communication and some element of joint undertakings and activities.

(5) *Flexibility*

Flexibility of approach in dealing with individuals is fundamental to partnership. Many recipients of professional services have complained bitterly about the generalisations and judgements of professionals—that a disabled child means a 'disabled' family, and that all parents need help to 'accept' that their child is handicapped. Generalisations and stereotypes need constantly to be questioned; no two parents are alike. If professionals want to establish comfortable and productive relationships with parents, they will need to explore with each family afresh what the situation means to them and how each family member can 'live with' and ameliorate the handicapping condition of one member. It is too easy for professionals to slip into routines. Being flexible takes time, but careful preparation is more likely to avoid wasted efforts in the long run.

Partnership means that parents can be involved with professionals in an active working relationship with frequent communication. But it does not mean that parents should be put under pressure to do so. Parents have a right to opt out of an active relationship with professionals; they may not want to act as a teacher to their child, or they may be prevented from doing so by real practical obstacles such as time, overwork, gross over-crowding, severe social or marital problems or sheer exhaustion. If we are serious about listening to parents, we must allow them to choose not to be involved in detailed collaboration. It may be a temporary stage—feelings and circumstances can change—or it may be how that particular partnership continues.

Many parents still regard professionals as special people with special training in working with disabled children. If, for exmaple, they have waited for years for their child to enter school, they need to believe that the child is passing into the care of highly skilled professionals, and that they can at last take a back seat.

Parents and professionals share similar concerns, yet have different perspectives, priorities and pressures. These similarities and differences pose acute challenges to them when they wish to form closer working relationships. The only predictable thing about disabled children and their parents is their diversity. But the effort is well worth while. A constructive partnership between parent and professional, utilizing the knowledge and skills of both, is the most likely way in which the needs of the disabled child will be fully met.

Overcoming Obstacles

In this final chapter, we draw together a number of examples of good practice and summarise suggestions which have been made for the development of better working relationships between parents and professionals. These examples come from communities at very different stages of development in their services. A number of examples of successful collaboration have come from countries and communities where parents have only the most limited resources and where the development of facilities and staff training are at a very early stage. In contrast, some of the richest countries experience difficulties in moving away from traditional practices which have in the past paid little attention to the importance of working towards better collaboration between parents and professionals.

Obstacles to Collaboration

The development of better working relationships is no easy task, and is beset by many obstacles. These have been mentioned by writers from many countries. We will therefore summarise some of the main obstacles to collaboration, and then try to suggest ways in which they might be overcome. We

shall see that some obstacles are common to both professionals and parents and that others are more specific to one group than to another.

(1) *Lack of preparation in training*

Few professionals have been adequately prepared by their basic training to learn about the experiences and points of views of parents, nor in general have they been provided with opportunities to discuss ways in which they might work in closer collaboration with parents. Although this is probably less true of recently trained professionals, we doubt whether many training courses have cause to be satisfied with the amount of time devoted to these issues.

It might be argued that students training to be teachers, social workers or doctors are still too inexperienced to take advantage of such information, and that there is no time on a crowded syllabus to air these issues. But failing to provide opportunities to consider and prepare for the development of effective working relationships with families could suggest to students that these are not perceived as important issues for practice.

Given the low priority attached to this subject in either basic or post-experience training, it is not surprising that lack of experience or confidence may make professionals hesitate to take new initiatives in working with parents. Feelings of anxiety and stress in adopting new roles and new relationships are understandable. Alternatively, over-confidence—the 'expert' role that "the professional knows best" is equally an obstacle to collaboration.

Just as professionals are inexperienced with parents, so the converse is also true. Teachers may not be aware of parental apprehension and even hostility to schools, arising from their own childhood experiences. Although these fears may make for uneasy first encounters, such problems can be overcome once teachers and parents have negotiated and agreed on a form of collaboration which suits both parties.

The training of professionals in aspects of collaboration with parents might include the following:—

(a) a brief rationale for collaboration;

(b) development of positive attitudes to parents by fostering understanding and empathy of parents' needs and difficulties;

(c) ways in which communication can be facilitated;

(d) range of activities and situations in which collaboration can be developed;

(e) providing situations in which professionals can "put themselves in the shoes of parents"—e.g. through role play and other simulation techniques.

(2) *Psychological and social distance*

Professionals, by virtue of their specialist training, tend to distance themselves from parents. Because they often perceive themselves to be of higher social and educational status, they may find it difficult to relate to parents as equals, even if the parents come from a similar social background.

The psychological and social distance of professionals from parents tends to result in quite unnecessary secrecy and mystification. Parents have also complained about professionals treating parents as 'patients,' their tendency to question the objectivity and accuracy of the information that parents have to convey about their children and their family and their failure to listen to parents' questions and concerns.

Working with parents as partners means that professionals need to learn to adopt a new role vis a vis parents. It requires them to shed some of the mystique and distance traditionally associated with the status of professionals. They will need to accept parents as equal partners in the task of working for the child's growth and development. Such changes of role and status can be difficult and painful. For example, it requires professionals to be open in their dealings with parents, to admit when they don't know or when they have made a mistake.

Professionals need to learn how to win the trust and confidence of parents. They need to learn about parents' feelings and their goals for the child, to enlist the experience which the parents already have, to learn and to understand how parents see their own situation.

A working relationship undertaken as a partnership requires not only the skills and techniques which professionals can offer but also an ongoing assessment by parents and professionals together of whether the child's and the family's needs are being met in the way they would wish. This requires consideration of the varying needs of families over time, of their feelings about their own competence and their own social and emotional resources as a family.

Professionals' lack of experience and confidence in working with parents is often matched by feelings of anxiety on the part of parents. They may agree that it would be beneficial for them to work more closely with teachers but may be worried in case they fail to meet what they regard as the teacher's expectations. They may also feel anxious about their own lack of ability and education. It is part of professionals' task to help put parents at their ease and to communicate in language that will be easy to understand.

(3) *Problems in reconciling the needs of the child with the needs of other members of the family*

It is only by getting to know the family as a whole that professionals can learn about ways in which the child is already benefitting from the help being offered by the family. They will also learn about the difficulties which many parents experience in seeking to balance the needs of the child with those of

other members of the family. Teachers and psychologists accustomed to planning for the individual child can easily overlook the implications of the child living in a family where there are many other demands to be met. The needs of brothers and sisters, of the mother and father as individuals and as a couple, of other relatives living with or close to the family—all these need to be considered by professionals when planning to involve the family in work with the child.

Sometimes, a social worker plays an important intermediary role in this situation. The training of social workers particularly emphasises the importance of thinking of the needs of the individual with a disability in the wider context of the family and of the immediate neighbourhood. This is one reason why a social worker is an important member of a multidisciplinary team. In addition, they work with families in order to explore their feelings about their child, their relationships as a family as well as with other professionals and service providers.

(4) *Unrealistic demands and expectations*

If parents and professionals have had only limited opportunities to work together, parents can have too little or too much confidence in the capacity of professionals to make progress with their child. If the child is making only slow progress, it is all too easy to put the blame on the severity of the child's impairments or on the lack of interest or lack of skills of those who are teaching the child. It is only when they begin to work together and realise the possibilities of active joint work and sharing experiences that a more systematic coordinated teaching programme can be developed.

On the other hand, some parents are so impressed by the progress made by the child that they may come to overestimate the teacher's skills and therefore underestimate their own potential contribution. This achieves the very opposite result from what is intended. In a true partnership, each person acquires an understanding of both the strengths and limitations of the other. Both parents and professionals are now beginning to understand how much they have to learn from one another and how much the progress of the child depends on their ability to work together in an atmosphere of trust and respect. This can only be created on the basis of a working knowledge of what each side can and cannot be expected to offer. This process requires time and understanding.

Once parents and professionals begin to work together, there is a danger that professionals may make excessive demands on parents. For example, parents may be asked to carry out frequent teaching sessions with their child, to make detailed records of the child's response to every session, to keep a diary recording use of language or the frequency of certain features of behaviour on which parents and teachers are currently working.

Although many parents welcome such detailed collaboration and shared activities, teachers are not always aware of the strains which this may put on a family's resources. They may also not be aware of the feelings of guilt and anxiety which may be aroused if parents find themselves unable to comply with the teacher's demands. Teachers in their turn will need to discuss with each family what kind of commitment of time would be consistent with the family's needs and resources so that parents do not put excessive demands on themselves.

After all, we know that some families are willing to work for hours at a time with their child if they feel sure that this is going to be of benefit. Some families would not necessarily regard it as a sacrifice of their time to work in this way. A heavy responsibility therefore falls on teachers and others to ensure that the demands that they make are consistent with the resources and needs of the family. This can only be ascertained by professionals asking the family in a sympathetic manner that enables families to share their real views.

(5) *Under or overestimating the child's abilities*

It sometimes happens that parents and teachers take a different view of the child's abilities. But teachers mainly see the child in school, whereas parents have more opportunities to observe the child in a wider variety of natural learning situations; furthermore, it is important that they should provide teachers with examples of the child's response to such situations. Here again, a constant interchange of information and ideas, as well as opportunities for joint assessment, may prevent mutual misunderstanding.

On the other hand, some parents find it difficult to accept teachers' assurances that the child is making progress. They may feel that teachers need to reassure themselves and their superiors of their skills and remain unconvinced that any real development has taken place which can be attributed to teaching. Some parents also find it hard to accept that teachers may have succeeded where they have failed. Here again, such problems are less likely if parents and teachers have worked together from the outset—by undertaking joint assessment, deciding together what the teaching priorities are and, above all in this context, agreeing on ways in which progress can be recorded.

(6) *Professionals' lack of support from their own management*

Although collaboration with parents is increasingly stressed in official policy pronouncements, direct help or support form management and superiors is often not available to staff at local level in actually putting such policies into practice. Greater management support might, for example, result in school staff being given time to visit parents in their homes, or being provided with additional staff to assist with home visits. In addition, it may be possible for a special room to be reserved in the school for parents to meet one another socially and to provide mutual support.

In conclusion, we will list a number of ways in which progress can be made in developing better working relationships between parents and professionals. Many of the suggestions have arisen directly from a consideration of the obstacles identified in this chapter, as well as from examples of good practice suggested in the replies to our enquiries. We will merely recapitulate some of the essential elements.

Common to all the suggestions that have been made is the principle that if people are to work together more successfully in the future than in the past, they will have to get to know one another better as human beings first and only secondly in their role of parents or professionals. In other words, it will be necessary to penetrate the barriers erected by society and its institutions, as well as by the individuals themselves.

(1) *The right and need to know*

The most important single need of parents is for information. Often, such information is available but is not easily accessible. Professionals and parents need to work together in order to ensure that all parents can gain access to information about local facilities and resources. Simply produced leaflets and information sheets can be made available, listing people and places where help and information can be found. Health centres, schools, public libraries and other public information centres could collect and display such leaflets and publicity about the availability of relevant information can be disseminated through local civic leaders, religious groups, business organisations and the media. Equally, professionals need to seek information that only family members can give about the child's life at home.

(2) *Opportunities for making contacts*

Parents and professionals can jointly organise a social or 'fun' event of some kind together—a school outing, a display of work, a school open day, a play or musical performance. Differences of role and status are easily forgotten when joint tasks are undertaken. People get to know one another as individuals: in the process, they form likes and dislikes or just remain neutral.

(3) *Parents contributing to professional training*

Although more parents are beginning to contribute to the training of professionals, it is still a comparatively rare event. Parents could talk to groups of students in training—e.g. doctors, nurses and other health professionals, teachers, social workers and administrators. There should always be opportunities for students to discuss issues with parents in small groups and to ask questions.

Parent groups can be asked to suggest parents who would be willing to meet groups of students from time to time and who would be willing to speak not only about their own personal experiences but also on the basis of their knowledge of other parents.

Because initial training courses nearly always have a crowded time table, in-service training or refresher courses for experienced staff provide additional opportunities for discussion, learning counselling skills through role play and so on. If these are single-discipline courses (e.g. primarily for doctors, teachers, etc.) opportunities can be taken to raise issues specific to the work of these professions. Mixed multidisciplinary courses provide better opportunities for professionals to learn about the experiences of parents, particularly in relation to problems of communication and coordination of services.

(4) *Parents attending professionals conferences and meetings*

Many of the conferences and workshops held for professionals could be thrown open to parents who wish to attend on the same terms as any other participant. This would add an essential dimension to the knowledge available at such meetings.

(5) *Professionals attending parents' meetings*

It is also useful for parents to invite one or more professionals to meet them on their own ground, rather than at a school or clinic. For example, parents may want to have an opportunity to question a teacher, a speech therapist or physiotherapist or psychologist about their work and about developments in their field.

(6) *Parents as policy makers*

If parents are seen as the consumers, or at least as the representatives of the consumers of the service, it is important that they should be fully represented on local and national policy making and advisory committees. In some countries, parents have a right to be elected as parent governors of schools, alongside community, teacher and occasionally student representatives.

There are a number of standard professional objections to the presence of parents on such committees. How is a parent selected? Whom do they represent and to whom do they report? Will they only be concerned with the needs of the age group represented by their relative? Some of the same objections could in fact be levelled against professional members of committees and most are in principle soluble. In fact, parents have a good case to be represented as of right. Furthermore, they can make an effective contribution precisely because they do not represent sectional service interests but speak for the consumer. However, as we have seen, consumers are increasingly speaking for themselves and demand to be represented on such groups in their own right.

(7) *Spreading the word*

More parents and professionals in many countries and communities are beginning to work together and to learn from one another. But examples of successful partnerships should be more actively disseminated, so that others can be encouraged by their example. Parents and professionals could collabo-

rate in writing articles in newspapers, giving talks on radio and television (both local and national), meeting local groups of citizens, business people, religious leaders, local politicians and civic dignitaries, inviting them jointly to meet the people working in and using the service. In this way, they would learn at first hand about the needs of the service and those who use it and work in it.

Working Together Works

Finally, the advice given in a Canadian handbook written for parents provides some useful guidelines on how parents and professionals can improve collaboration (adapted from Brynelsen, 1984).

Parents:

—don't be afraid to ask for help;

—ask to bring a friend or relative with you when you meet professionals;

—ask for clarification if information is not clear to you;

—challenge professionals if you disagree—be honest about home happenings and explain practical restrictions on time and energy;

—seek other kinds of help if you need it (where it exists);

—if you are not pleased with professionals' advice or help, tell them;

—show your appreciation for good service and attitude.

Professionals:

—ask for parents' opinions: then show that you value them;

—give parents recognition for their strengths and successes;

—tell parents they are experts too, through specific and accurate comments;

—do not patronise;

—believe the parent: children do act differently in different settings;

—show respect for children and value them as persons;

—accept peoples' right to be different, avoid generalising and stereotyping;

—listen to parents, sometimes they know more than you;

—do not press parents to participate.

Partnership between parents and professionals is working in many countries and communities. It is still at an early stage of development and there are many obstacles to be overcome. But there can be no doubt that the resulting benefits to children and young people with disabilities amply repay the effort involved for parents and professionals in working through a sharing of knowledge and skills.

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CULTURAL AND ETHNIC ASPECTS OF FAMILY SUPPORT SERVICES FOR PARENTS OF A CHILD WITH A DISABILITY

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The author wishes to express his gratitude to Michael Reed for his assistance in the preparation of this article.

Introduction

Over the past decade rehabilitation services have undergone a process of transition from focusing on the individual with a disability or handicapping condition to recognizing and emphasizing the importance of the family framework in understanding critical professional issues and developing more effective services. This trend has enhanced the interest of rehabilitation professionals in the accumulating knowledge of family structures, functions, dynamics, role differentiation, interaction patterns in general, and family functioning and coping under stressful conditions in particular (Drotar, Crawford and Bush, 1984; Power and Dell Orto, 1980). The vast majority of the existing body of knowledge, based on clinical and empirical studies (Masters, Correto and Mendlowitz, 1983; Patterson and McCubbin, 1983; Sabbeth, 1984), monographs (Zucman, 1982), books (DeLuca and Salerno, 1984; Turnbull, Summers and Brotherson, 1984; Wright, 1982), conferences and legislation have their source in western countries, and mainly in the U.S.A. However, the knowledge and experience gained from such sources mainly reflect the values, norms, belief systems and patterns of coping of the 'majority' within the modern western society. Thus, although the family is recognized as a universally significant unit, it would be an oversimplification to assume that the family unit behaves, functions and copes in the same manner in different cultural and ethnic contexts, particularly when under stressful conditions. More and more social scientists are recognizing the importance and the utility of cross-cultural and cross-ethnic studies for expanding our theoretical and practical knowledge of family patterns and activities in the general population (Lee, 1984; McGoldrick and Preto, 1984). Unfortunately, as recently emphasised by Turnbull, Summers and Brotherson (1984), little research has been conducted on reactions of different ethnic groups in the U.S.A. to the presence of a disabled member within the family, and even less attention has been paid to cross-cultural studies of this issue. In today's multi-cultural countries like U.S.A., Great Britain and Israel, the

rehabilitation service provider needs to be astutely aware of the ethnic and cultural impact on the reactions and attitudes of the family toward a member with a disability. As long as the impact of ethnic and cultural factors influencing families are de-emphasized or neglected by policy makers and service providers, it can be assumed that the whole range of professional family support services will be limited in their effectiveness.

Needs of, and Services for a Family with a Child with a Disability

Although parents may want babies, and be glad they have them, they are often dismayed at what the transition to parenthood entails. In a study undertaken by Miller and Sollie (1980), parents of 'normal' babies reported experiencing such positive aspects of parenthood as: a sense of fulfilment, a new meaning in life and a strengthening of the husband-wife bond. At the same time, these parents also reported negative aspects of parenthood which included: the physical demands of caring for an infant, strains on the husband-wife relationship, emotional costs of parenthood, adult activity restrictions, and financial and career restrictions (Sollie and Miller, 1980).

One of the early tasks of parenting is to resolve the discrepancy between the idealized image of the baby, developed by the parents during pregnancy, and the actual appearance of the real baby (Solnit and Start, 1961). If a baby is born with a developmental and/or physical disability, this discrepancy is much greater. This may lead to parental grieving over the loss of the "dreamed-of baby" in order to make the necessary adjustments to begin the process of "attachment" (Bristor, 1984). Thus, it seems reasonable to assume that raising a child with a disability may effect the reported positive aspects of parenthood, but will certainly add additional burdens surrounding the negative aspects and tasks of parenthood.

Numerous studies appearing in western professional literature have dealt with the special needs, problems, difficulties and obstacles encountered by parents of a child with a disability (Kazak & Marvin, 1984; Longo & Bond, 1984; Zucman, 1982). It is suggested that the relatively large body of existing knowledge concerning these parents' complex predicament be approached from a two-level perspective: (1) the psychosocial stages of parental reactions to their child with a disability; and (2) the impact of the child's condition on various familial life spheres. Understanding family needs through the combination of these two levels may give clearer guidelines to professional family service providers as to what to give, when to give, how to give and if, at all, to give support to these parents.

The psychosocial process of parental reactions to the onset of a handicapping condition of their child includes a series of stages that may last for a relatively long period of time. Following the shock of finding out about their child's disability, parents will probably deny the existence or seriousness of the condition, and may isolate themselves from others to avoid confronting

reality. As parents leave the protection of denial, feelings of guilt and anger are likely to occur. Parents may blame the professionals involved in their original diagnosis and may begin to "shop around" among other professionals in an attempt to find a cure or at least a better prognosis. When parents begin to realise the child's irreversible condition, elements of depression may appear. Finally, at the stage of acceptance, parents have not only to face dealing with the loss of the expected 'normal' child but also the much more complicated task of rearing a child with a disablity. In revising the abovementioned model, Berry and Zimmerman (1983) contended that parents may experience any former emotions again (separately or in sequence) and then turn to acceptance.

Grieving parents and other family members need to be able to do more than simply acknowledge their feelings. They need help to understand the cause by exploring what is causing the feeling and grow through their pain in order to be able to cope with present and future situations. Bristor (1984) proposed a series of guidelines to help understand and facilitate the grief process among family members of a child with a disability. These included: (1) awareness of emotions surrounding the experience of having a child with a disability; (2) accepting these emotions as 'normal' and legitimate; (3) establishing an open familial atmosphere in which emotions can be freely expressed; (4) making time for parents' self-care; (5) encouraging the involvement of friends and/or existing social support resources in providing necessary emotional support; and, (6) when necessary, providing counselling services.

As infants and children grow older the demands placed on family members, and particularly parents, involve more and more life areas. Sabbeth (1984) contended that the impact of illness on a family could occur in any of the many life spheres—financial, social, somatic and behavioural. Patterson and McCubbin (1983) summarized the hardships experienced by families who have a chronically ill child—

1. medical concerns related to obtaining competent medical care;
2. the burden of increased tasks and time commitments such as providing special diets, cleaning and/or therapy;
3. increased financial burdens;
4. need for housing adaptions;
5. differences in school experiences;
6. modifications in family activities and goals such as reduced flexibility in leisure time;
7. strained family relationships resulting from overprotectiveness, jeopardizing the child's development of 'independence'; and,

8. social isolation possibly due to limited mobility or embarrassment in front of relatives and friends.

In addition, Bubolz and Whiren (1984) emphasized that locating and obtaining access to the medical, educational, social and other support services needed, placed still additional demands on the family's energy supply. Even though a family of a child with a disability may continue to function using internal energy and resources in a more or less stable level, they are nevertheless extremely vulnerable to external sources of stress such as inflation, unemployment or cancellation of special education or other programs. Since, in today's modern world, a child with a chronic illness or disability often lives for increasingly longer periods of time, the demands on material and psychic energy and other family resources may be exhausted. Thus, the option of institutionalization may become a feasible proposition.

Based on the suggested two level approach to parental and family needs, as recognized in modern western society, the following considerations are presented for incorporation in the formation of family support services:

In the early stages of the onset of the handicapping condition (physical or developmental disability), be it at birth or later in the child's life, the following family support services are recommended:

1. crisis intervention counselling.
2. provision of information relevant to the psychosocial and medical development of the specific infant or child condition.
3. counselling—long-term personal and family adjustment to a disabling condition and, if appropriate, genetic counselling.
4. special assistance and/or housing assistance services—diet and nutrition information when needed; home care; provision of special equipment and housing modifications.

As the child grows up additional services may be required. These may include—

5. reaching out programs directed at the unserved and underserved involving referrals, the dissemination of information concerning rights, service availability and advocacy.
6. training programs for parents and other family members aimed at enhancing care—giving skills while providing a peer support framework for participants.
7. respite care providing temporary relief for family care-givers through medical institutions, community-based facilities or voluntary agencies.

8. programs offering financial assistance, modification of required equipment for the growing child, transportation services and a variety of recreation facilities.

The family service delivery framework suggested here, is a modification, primarily through rearrangement, of the family support services presented in the NYSSOMRDD draft report (1985).

The recent proliferation of specialized governmental, nonprofit and private organizations has required many parents to obtain a variety of services from several different organizations, especially in cases of children suffering from chronic problems and the family from economic difficulties. In western countries communities are recognizing the growing need to develop complex service delivery systems that can provide the child with a disability with a coordinated, continuous access to many services for long periods of time. In analysing the future of human services Austin and Hasenfeld (1985) emphasised the effectiveness of the entire service delivery system, rather than that of any single program of a single agency, as the most important criterion for evaluating the successful provision of human services.

Cultural and Ethnic Factors as Determinants of Reactions to a Child with a Disability in the Family

1. Cultural dimensions and attitudes toward disability

In today's multi-cultural and multi-ethnic societies one may wonder whether 'needs identification' and 'family support services,' developed primarily in the U.S.A., are effective among minorities in the U.S.A. and/or among other socio-cultural groups throughout the world. For the purpose of this article the term 'culture' will be broadly defined as to include such elements as customs, ethnic values, language, religion, role differentiation, kinship relations and geographical location.

In reviewing social science literature three main dimensions of culture relevant to this presentation may be identified. The first relates to the transitions from traditional to modern family systems (Parsons, 1970), the second to families from homogenous versus heterogenous backgrounds (Palgi, 1968), and the third to the differentiation between shame-oriented versus guilt-oriented cultures (Benedict, 1946; Lynd, 1958). While the first two dimensions have been dealt with extensively, family studies have often overlooked the third dimension. Shame and guilt differ from other affects in that they may be understood through their direct references to internalized social norms: the disruption or violation of these social norms may lead to "shame" —a response to role transgression or "guilt"—a response to moral transgression (Piers and Singer, 1953). The manner in which an individual will react and adapt to a stigmatic condition will reflect the prevailing socio-cultural approach to "transgression." Thus it is reasonable to assume that in a "shame-oriented"

society most individuals' reactions to a stigmatizing condition, such as a physical disability, may involve attempts to hide the condition from the immediate surroundings, while in a "guilt-oriented" society individuals' reactions to such a condition may involve ongoing self-blame and a strong sense of personal responsibility for the condition. Shame interrupts, exposes and disrupts a unitary sense of an individual and his/her family, while guilt evaluates, judges and condemns the individual and his/her family.

Families are as diverse as the cultural groups to patterns and many other facets of their lives are affected by their cultural background. This cultural background gains expression through beliefs, values and coping styles which form the basis of determining family interaction processes in general, and a family's interaction to a member with a disability in particular (Turnbull, Summers & Brotherson, 1984). All families will be influenced, to some degree, by the prevailing attitudes toward the disabled found in their own cultural environment. For example, numerous cross-ethnic and cross-cultural studies have found significant differences in the attitudes toward the person with a disability among various societal groups. Black Americans have been found to differ in their attitudes toward a person with a disability when compared to White American (Grand and Strohmer, 1983; Jordan, 1971). Asians have been found to differ in their attitudes towards a person with a disability when compared to Americans (Tseng, 1972). Significant overall differences have been found among Latin American and Asian, African and Asian, and Middle Eastern and Asian student attitudes toward the disabled (Trimino, 1983). Finally, research undertaken in Israel has revealed significant differences between attitudes held by Israeli Jews and Israeli Arabs toward a person with a disability (Florian, 1982; Florian and Katz, 1983; Shurka and Katz, 1982).

In some cultures it is not uncommon for a child with a disability to be fully accepted and treated as a cherished family member. The community may reinforce the family's feeling of protectiveness. In other cultures, the disabled are viewed as permanent children and are overprotected and kept away from the stresses of daily life. In still other, more extreme cases, "defective" children are abandoned or left to die (DeLuca and Salerno, 1984). However, it may be reasonable to assume that, regardless of the prevailing cultural attitudes toward a child with a disability, families of such children will be socially stigmatized. The ways in which families experience this socio-cultural stigmatization will vary depending on possible combinations of the three cultural dimensions: 1) traditional versus modern family systems; 2) homogenous versus heterogenous; and 3) 'shame' versus 'guilt.' In order to provide a more comprehensive view of these families, a fourth dimension may be added to the abovementioned dimensions—minority versus majority status. For example, when serving families of a member with a disability who also belong to a minority group, the family service provider is

confronted with a client who has a double minority status: disability and ethnicity. Families with a double minority status are generally recognized as forming a large part of what has been referred to as the "unserved" or "underserved" population (Snowden, 1982).

2. The Case of Ethnic Minorities in the U.S.A.

In order to illustrate the special conditions, problems and difficulties of families of a child with a disability, three American ethnic minorities will be briefly examined.

A. *Pacific/Asians:* Chan (1978) described selected experiences of Pacific/Asian families with developmentally disabled children in America and found that these families had been subjected to negative experiences which service providers, as well as the general public, often failed to recognise. The effect of these families' double minority status experiences compounded the difficulties which typically exist among families child with a developmental with a disability. Many ethnic families with such children could not be legitimately evaluated and understood in terms of strictly clinical perspectives. Chan (1976) further contended that problems of handicapped Asian/Americans were unique because members of this group, particularly the Chinese, frequently perceived handicapped persons as permanently unsound or incomplete individuals who have been cursed for sins committed by their ancestors or themselves. Thus the Chinese had little interest in remedial therapy, lacked institutions for the elderly, mentally and physically handicapped and placed the onus on the family to care for less able members.

B. *Black Americans:* One of the most striking characteristics of Black families (especially poor Blacks) is their reliance on an elaborate family network involving extensive sharing of resources and responsibilities (Ball et al, 1979; Stack, 1974). This reliance might, in some way, explain the failure of Black families with disabled members to use 'services' or even to perceive a need to seek outside help (Justice, O'Connor and Warren, 1976). Firstly, many years of interacting with oppressive and patronising social service agencies has left these families suspicious of anything the 'White' service system has to offer (Stack, 1974). Secondly, the strong and flexible family system provides the answers that many middle-class White families do not have. Respite care, for example, is simply not an issue, since everyone in the family network is responsible for all the children (Turnbull, Summers, Brotherson, 1984). Support for this view may be found in Wallace's (1980) study which revealed that Black mothers, when compared to White mothers, had high (positive) attitudes toward the maintenance of their retarded children at home and expressed satisfaction toward the reactions of family, friends and community.

Turnbull, Summers and Brotherson (1984) maintained that any program to serve Black families would need to look beyond the nuclear structure and help the family capitalize on the strengths available through the extended

family network. Such a program would also need to explore ways of becoming *part* of the network through informal exchanges to build a sense of mutual obligation and trust.

C. *Mexican-Americans:* The social science literature typically portrays Mexican-Americans as being embedded in supportive social networks composed of strong friendships and extended, cohesive family systems (Mandel, 1980). Falicov (1982) described Mexican families as relaxed about developmental milestones although often encouraging lengthy dependence on the family. Kunce (1983) observed that for some Mexicans "disability" is something to be hidden. Children and infants, for example, may not be referred for appropriate treatment which in turn may lead to a more chronic disability. Mexican parents expressed feelings of protection and fatalistic acceptance of their child with a disability possibly due, in part, to their religious convictions (Marion, 1980). For some Mexican-American families their original language, customs and traditions remain of great importance. Luetke (1976), in her study of Mexican-American parents of hearing-impaired children found that 27% of the parents studied preferred their child's instruction to be in Spanish and 20% preferred bilingual instruction. Moreover, in addition to preferring service provision in their own language, Ruiz and Padilla (1977) found that Hispanic families expected an active, goal-oriented type of service intervention.

3. The Case of Arab and Jewish Communities in Israel

Israel's two culturally separate populations of Arabs and Jews in principle share the same access to the physical environment, live under the same legislative system and receive the same centralized governmental health, education and social services. At the same time both the Jewish majority and Arab minority have made great efforts to maintain their distinctive cultural heritage through the preservations of customs, values, norms, traditions, language and relationship affiliations. One of the most pronounced expressions of this effort to preserve their cultural heritage may be seen in the differing family systems found in the two communities. The Israeli Jewish family system is mainly a heterogenous, nuclear, modern framework which tends to consist of democratic family relations similar, in many ways, to other Western countries (Davids, 1983). Consequently, this kind of system is characterized by emphasising emotional relations and de-emphasising strict role differentiation between family members (Burgess, Lock and Thomas, 1971; Parsons, 1970).

The Israeli Arab family system, although undergoing a continual process of modernization, still emphasises the homogenous, traditional, authoritarian framework. The extended family continues to play a central role, with a definite hierarchical structure in terms of formal status and distinct role differentiation (Al-Haj, 1983; Antonovsky et al, 1978; Patai, 1973; Sharabi, 1975).

As in other multi-cultural countries Israeli Arab and Jewish societal attitudes toward people with a disability differ according to the cultural background of each community. In an extensive review of research involving Israeli populations Florian and Katz (1983) concluded than Jews of Oriental origin (born in Arab Moslem countries) appear to have more negative attitudes toward the disabled than Jews of Western origin and background. In addition, Arabs appeared to have less positive attitudes toward the disabled and disability compared to Jewish citizens. Florian and Katz (1983) offered a possible explanation for these cultural differences through the characteristics identified by Ausubel (1955) of the 'guilt' and 'shame' societies. The Israeli Jewish societal reaction to physical disability, characterized by a sense of guilt and consequently a strong sense of reasonability, limit the impact of the spread-effect. According to Wright (1982) this spread-effect is often the core of negative attitudes toward the disabled. Thus the sense of guilt may, in fact, generate more positive attitudes. In contrast, what pressures the Arab is probably not guilt but shame, or more precisely the psychological drive to escape or prevent negative judgement by others (Patai, 1973). It may be suggested that this sensitivity to what others have to say predisposes more negative attitudes toward a person who displays deviant behaviour and/or deviant body characteristics. These differing culturally-based reactions to a person with a disability have an impact on how parents relate to and cope with their child with a disability.

In the last twenty years several Israeli studies have examined parent's attitudes toward their child with a disability. The results of these studies appear to indicate that even within the Jewish immigrant population differences exist between Jews of Oriental origin (born in Arab and Islamic countries) and Jews of Western origin (born in European, American and other westernised countries). Weisman and Chiegar (1965) examined the attitudes of parents of cerebral palsy youth and found that parents of Western origin had more 'realistic' attitudes as compared to parents of Oriental origin, who tended to have more 'fatalistic' attitudes. Mandel, Palgi, Pinkis and Greenberger (1969) surveyed the attitudes of parents of children with cerebral palsy from various Jewish ethnic backgrounds. The results indicated that parents of Western origin tended to blame medical negligence for the child's condition, whereas the parents of Oriental origin tended to blame fate or themselves for the condition. Moreover, parents of Western origin were likely to think that the child could benefit from vocational guidance, while the parents of Oriental origin often expected the child to be institutionalized.

More recent studies have compared the Arab versus Jewish parents' attitudes and coping styles toward their child with a disability. In a study involving parents of a child with one of a variety of disabilities i.e., orthopedic, internal injuries and sensory disability, Shurka and Florian (1983) reported that Israeli Arab parents thought their child required much more

time in performing daily living activities compared to their Israeli Jewish counterparts. Jewish parents tended to report that their child with a disability made independent decisions while Arab parents tended to report that their child's decisions were made within the family framework. Most of the Jewish parents thought that their child with a disability was capable of work (full-time or part-time), while half of the Arab parents thought that their children were unable to work. In another study, using the same population, Florian and Shurka (1981) found that the two cultural groups coped differently with additional economic and financial demands arising from the child's disability. Arab parents preferred to sell properties in lieu of the father taking on additional work, with the mother going to work was seen as the less preferred alternative. In contrast, Jewish parents viewed the mother going to work favourably, while property sale was the less attractive alternative. Concerning parental approaches to community resources for aid, Israeli Arab parents tended to rely on the extended family while Israeli Jewish parents tended to rely more on personal resources, their contact with outside resources mostly limited to professional rehabilitation services.

In summarizing the abovementioned review, it seems reasonable to conclude that cultural factors, whether related to ethnic minorities in the U.S.A. or the Jewish and Arab communities in Israel, should be definitely considered in understanding and evaluating the special needs of parents of a child with a disability and consequently the preparation and delivery of family support services.

Implications for Service Delivery

Families of a child with a disability have to deal with a wide variety of life difficulties and obstacles which require a continual involvement in their resolution. Based on Western professional literature it is suggested that the needs of such families and the provision of family support services be viewed from a two-level perspective—1) the psychosocial stages of parental reactions to their child's disability, and 2) the impact of the child's condition on various familial life spheres. It is further proposed that in today's culturally diverse societies policy makers and family service providers must incorporate cultural and ethnic factors, influencing such families, in the design and implementation of family support programs. Practical implications for such programs may be provided by the combination of existing knowledge of cultural and ethnic factors influencing the family of a child with a disability (DeLuca and Salerno, 1984; Turnbull, Summers and Brotherson, 1984) and the principles of cross-cultural counseling (Sue, 1981).

Following are some suggestions relating to the abovementioned two-level perspective.

Level 1: Parental psychosocial reactions

Professionals need to be aware of the fact that culturally diverse families may not exhibit the same emotions and behaviors found among Western families. The psychological and social significance of giving birth to a child with a disability and raising such a child may not necessarily elicit the same emotional reactions, which are often described in modern professional literature, among parents from diverse cultural backgrounds (Marion, 1980). For example, clinicians who are primarily trained in the implementation of modern models of "grief and mourning" reactions may inadvertently inhibit the natural "mourning" process among parents from diverse ethnic and cultural backgrounds through their misunderstanding of culturally expected expressions of emotions. Moreover, throughout the grief-therapy process clinicians may request a relatively high degree of self-disclosure of feelings, thoughts and aspects of the marital relationship on the part of the parents which may be incompatible with the parents' cultural and ethnic values. This may be the case when working with families from Asian-American and Chicanos backgrounds (Sue, 1981) or Arab Israeli versus Jewish Israeli parents (Florian, 1986). Therefore, in light of the above, several specific recommendations can be made:

1. Family support service practitioners should familiarize themselves with the culturally accepted forms of emotional expression in general and the emotional reactions and attitudes to a child with a disability in particular, of the various cultural groups which make up their client population.

2. Family support service practitioners should define counseling goals and coping patterns which are consistent with the life experiences, religious beliefs and cultural values of the families served.

3. The professional literature has recognized that effective counseling and therapy may be enhanced when both the practitioner and client share the same world view, similar cultural/racial heritage, ethnic identification and experiences in society (Sue, 1981). However, in reality, among most service providers this is not the case. Thus, it is recommended that professionals working with families from diverse ethnic and cultural backgrounds should select and employ those intervention techniques found most appropriate to each cultural group. 'Minority' families may not be oriented toward traditional, verbal, self-exploratory therapies, may not be prepared for the ambiguous nature of counseling, and, indeed, may prefer active/directive approaches rather than a person-centered approach to counseling. Furthermore, professionals should learn how to interpret culturally-bound, non-verbal aspects of communication such as body language in relation to distance (proxemics), body movements and gesticulations (kinesis), eye movements, facial expressions and mimics. Such knowledge could enhance the professional's understanding of 'minority' family members who may sometimes have difficulty in only verbally transmitting their emotional conditions.

4. In order to implement the abovementioned recommendations, training programs for professionals should not only incorporate a cognitive understanding of the cultural impact on behavior but also encourage actual experience and involvement in the life-styles of the families they serve.

These recommendations may be achieved through one of two ways:

—(a) active acquisition of verbal and non-verbal manners of communication, customs and behavior patterns characteristic of the cultural and ethnic groups served; or,

—(b) intensive study and apprehension of values, symbols, customs, religious beliefs and other aspects of specific cultural and ethnic groups in relation to the values, symbols, customs, religious beliefs and other aspects of the service provider's own cultural background. By recognizing differences and possible contrasts in behavioral pattern characteristics of each culture the practitioner may develop a greater sensitivity and deeper understanding of the client's life-style, thus enhancing his/her competence to provide effective services to families from diverse cultural backgrounds.

Level II: Impact on familial life spheres

In the delivery of long-term services to parents of a child with a disability policy-makers and family support providers need not only to consider general cultural attitudes towards disability but also the daily life activities and needs of such families within their specific cultural and ethnic communities. In this context it should be emphasized that additional variables such as education, income and housing etc. in interaction with an ethnic 'minority' status may create supplementary hardships for these families. Thus, professionals need skillfully to utilize the entire complex service delivery system so that the family may benefit from the full range of potential resources appropriate to the needs of the unique family.

Based on the review of the literature and the abovementioned contention, several practical recommendations can be made:

1. Based on careful evaluation of the ethnic-'minority' family's needs, service providers should classify, disseminate and clearly present the range of support services existing in each family's cultural community, what benefits are obtainable from these services, the family's right to utilize these services and the cost of using these services. This information should be supplied using lay terms and, when possible, in the native language of the family whether using verbal communications or written material.

In modern western society changing life-styles appear to have encouraged a greater interest in self-fulfilment and individual freedom among family members. This can militate against taking on the responsibilities of family based care. (Agosta and Bradley, 1985). However, such may not be the case among ethnic-minority groups, influenced by traditional family values, who live in such societies. As a result of the growing recognition that each family is

unique and needs varying types and amounts of services, support services have increasingly moved from a pre-set pattern of giving the same services to everyone to a more individualized program approach (Weisz, 1983). Parents of a child with a disability from diverse ethnic minority groups may be viewed as a good example of the importance of this process.

2. Before providing long-term services of such 'minority' families service providers should consider the family's unique needs and their available resources as a basis for deciding whether to supply services at all and, if so, what services to provide, how to provide them and to whom. Furthermore, service providers should acquaint themselves with the family's specific cultural customs, the family structure and sex-role differentiations, the family decision-making processes and differential cultural expectations of the father's and mother's familial roles and responsibilities. In addition, the professional should evaluate the potential help that the parents and their child may receive from extended family members and the existing natural social support networks found in the diverse cultural groups. For example, in a traditional, "shame-oriented" culture "direct" help in such areas as financial assistance, housing, respite care and transportation may be perceived as offensive in nature. In certain ethnic-minority groups, particularly among traditional, homogenous family systems, such assistance is expected from the extended family. Thus, direct material help proposed by community-based agencies may be seen as "humiliating." Alternative programs for such families may include teaching the parents how to organize the child's daily care through the effective utilization of existing familial and social support networks, training the caring-ones to modify the manner in which help is provided according to the needs of the child at various developmental stages, assisting in the rearrangement of the housing order so as to facilitate the management of the changing needs of the child with a disability, providing information and new developments in appropriate medical and technical equipment that may improve the child's functioning and, when needed, encouraging the use of existing health and medical care programs.

3. As the child grows up and enters the education system the family service provided should be aware of the sensitivity of the parents from diverse ethnic and cultural backgrounds in regard to available school programs and, later, the vocational training of the child. Special attention needs to be paid to the "double minority" status of these children particularly in the area of evaluation of intellectual potential and the consequent appropriate placement in the education and vocational training system. Periodic assessment of the child's cognitive ability and skills should be performed using "cultural-free" tests which have also been proven appropriate in evaluating a child with a disability. Another issue relevant to the child's education and recreation programs is related to the "integration" versus "segregation" controversy. Although it has become quite accepted for pro-

fessionals to recommend "mainstreaming" of a child with a disability, when dealing with children with a disability from a diverse ethnic and cultural background a difficult dilemma arises. In such instances the service provider should frankly discuss with the parents the advantages and disadvantages of each option and decide with them, on an equal basis, what is the best long-term alternative for their child. Through this collaboration the service provider may help the parents overcome feelings of frustration and anger described by Marion (1980) as a reaction to an education system that parents of ethnic minorities may feel promotes mental retardation and emotional disturbance as the only two appropriate despositories for their child.

4. Professional literature and field practice recognize the importance of parental participation, primarily through such organizations as self-help groups, in designing programs for their child with a disability. The rationale for the self-help emphasis rests, in part, on giving parents a greater stake in the process which they largely control and which respects their dignity and rights (Agosta &Bradley, 1985). However, this progressive, modern idea of consumer involvement in service delivery has often not been utilized by 'ethnic-minority' parents of a child with disability. Marion (1980) contended that such parents usually do not belong to these organizations because of "mistrust" of the majority. The outcome of this "non-alliance" has been a feeling of isolation on the part of parents of culturally different children. Feelings of isolation may have their source in the "double-minority" status of these parents. For example, self-help groups discussions by "majority status" parents may include issues, needs and opinions concerning their children and themselves that may not necessarily be shared by the minority parents. Furthermore, even in situations involving a shared, common interest between 'majority' and 'minority' parents, the accepted ways of coping or solving these issues may be inappropriate or impractical in the "minority parent's" context. Thus, the family service provider should carefully evaluate the attitudes of their ethnic minority clients toward such organizations. Only when seen as appropriate to the parents' cultural values and customs should the service provider encourage and assist parental involvement in those self-help groups whose management incorporates a particular cultural perspective.

In order to implement the abovementioned recommendations both policy makers and professionals who provide family support services to ethnically and culturally diverse parents of children with a disability should actively seek their close and continuous collaboration. In pursuing this important goal professionals should:

(1) genuinely respect the feelings, values and beliefs of the client group, thus maintaining and enhancing the positive self-esteem of these parents.

(2) be aware of the needs and strengths of all family members.

As pointed out by Lipsky (1985), professionals all too frequently focus on the emotional difficulties faced by family members while not giving sufficient recognition to the family's "real difficulties" in caring for their child. In the light of this contention, family service providers should carefully and continually examine their methods of practice: Does it answer the actual needs of the client or does it answer a professional's need, often limited by insufficient knowledge? This question is particularly true in the case of families with a culturally diverse background. Through relevant knowledge, enrichment, programs and, appropriate supervision family support providers may effectively deal with this dilemma, thus further enhancing the indispensable collaboration of their clients.

Conclusion

In conclusion, it should be recognised that due to our relatively limited empirically-based knowledge all the above recommendations should be considered carefully. Indeed, an extensive review of the professional literature revealed the existence of only a handful of studies, undertaken outside the U.S.A. and Israel, which investigated parental difficulties in coping with a child with a disability. These studies, carried out in Norway (Storhaug, 1983), Scotland (Tarran, 1981), Nigeria (Enwemeka and Adeghe, 1982; Ojofeitimi and Oyefeso, 1980), Australia (Strom et al, 1981), New Zealand (Hornby and Murray, 1983) and some others reviewed by Zucman (1982), investigated specific problems of parents and did permit cross-cultural comparisons. Thus, further research efforts incorporating cross-cultural studies are needed in order to expand and deepen our understanding of the family dynamics surrounding a child with a disability among diverse cultural and ethnic backgrounds. Knowledge gained from such research could only improve the effectiveness of policy making and delivery of adequate family support services.

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A MOTHER-CHILD PROGRAM IN ISRAEL
by Annat Kalir, M.D.

In Israel, the traditionally extended family was accustomed to taking care of all its members, including incapacitated individuals. Rapid socioeconomic developments brought about a change in the family structure. The nuclear family living in cities, far away from parents and siblings, found it difficult to cope with the special needs of the disabled child, thus pressing for placement in a residential institution. The widespread employment of mothers added to that pressure. The current trend is to provide family support services to enable the handicapped child to grow up in his own family, away from residential institutions.

For example, beginning in 1981, parents of disabled children from age 3 to 18, living with their families became eligible for a special payment from the National Insurance Agency. This pension is destined to compensate for extra expenses of a family earning less than a fourfold average household income. The criteria for the child's eligibility are based on a modified Activities of Daily Living scale (ADL) used normally for disabled adults, thus automatically excluding handicapped children below the age of 3.

This Act constitutes an important move towards encouraging parents to care for their handicapped child within the family. It is, however, regretful that it was not directed at motivating parents of handicapped children from birth on instead of age 3, and, also, that the rationale behind this legislation was not based on provision of means for developing the child's skills rather than on compensating for his disabilities.

In the early years of the State necessity dictated concentration on physical problems such as toxemia of pregnancy, nutrition problems, infectious diseases etc. Once these pressing issues came, more or less, under control, emphasis in family services, particularly the Mother-Child Centers, moved to behavioral problems, and later to bridging the social gap between the different ethnic groups of the population. The center of focus shifted from questions of life and death to problems concerning quality of life for the individual and the family, including these with a handicapped family member.

In the last two decades promotion of health, primary prevention of handicapping conditions, early detection of children with deviations from the norm and the care of children who are handicapped from birth or early life, have become the main tasks of the Mother-Child Centers.

A unique feature of the Mother and Child Health (MCH) system in Israel is the continuum of the health care of the individual. The care starts with the preconceptional stage, it goes on to prenatal care, through childhood and adolescence. The same personnel follows the individual through the various stages of development. Health records are designed to follow each child from infancy to adolescence. This continuity creates favorable conditions for the detection of risk factors to the development of the child and to early finding of deviations from the norm.

FAMILY SUPPORT IN SWEDEN
Inger Claesson Wästberg

For several decades in Sweden the rights of people with mental retardation to habilitation have been written into a special act. A total revision of this act came into effect July 1, 1986. The rights have been more closely defined and the objectives stated of enabling persons with mental retardation to live like other people and together with other people.

The new Act specifies five forms of free services which the County Councils have to provide persons with mental retardation, childhood psychosis, and persons who after the age of 16 suffer brain damage leading to substantial and permanent intellectual impairment caused by tumors or accidents. They include:

- Advisory support from various experts,
- Daily activities for persons above school age,
- Respite care for parents,
- Foster-home or boarding home for children, and
- Group homes for adults incapable of independent living.

Basic Principles

The principle of normalization is fundamental. It means that the living situation for persons with handicap should be similar with that of other people.

The integration principle is an important part of efforts to achieve normalization. Persons with handicaps must participate in social life together with and on the same terms as other people. The realization of this principle demands both material and personal support.

For the parents of children with handicaps it is very important to be given access at an early stage to good initial information, general education and supplementary education. These measures should be combined with practical forms of support such as assistance with care and supervision and short-term care. All support should be designed in response to individual needs and should emanate from the general support given by the community to parents. It must be made readily accessible, but it also needs to be supplemented. General parental education is one example; parents of children with handicap must be able to take part in this education on the same terms as parents of other children, but it needs to be supplemented by focusing on the handicap and organized in such a way that parents can meet other parents in a similar

position. Where supplementary education is concerned, the Habilitation Committee is responsible for ensuring that it materializes.

Many children and young persons with handicap, as well as their families, have difficulty in availing themselves of the resources controlled by various sponsors. Moreover, they may need extra support, a safety net, in addition to regular services. The habilitation organization should be capable of serving as a safety net of this kind. Therefore, a co-ordinated County Council habilitation organization is recommended for those handicapped children and young persons within each County Council area requiring special support and services.

The responsibilities include co-operation with other fields, such as medical care, schools, social services and State educational facilities for children and young persons. One of the first steps towards the realization of this model is the amalgamation of existing organizations, above all those concerned with mental retardation and persons who are physically disabled or with other physical handicaps.

Service Organization

The habilitation organization is divided into district teams. These teams include officers representing psychological, social, medical and educational spheres of competence. Each team numbers between five and ten persons in order to be capable of providing children and their families with reasonable support. The team is not attached, either organizationally or physically, to hospitals or hospital management areas.

The tasks of the district teams comprise basic or supplementary diagnostics, the assessment of therapeutic requirements, treatment and/or the arrangement of therapeutic measures. Their tasks also include the provision of information and education for personnel and parents, and it is their job to include public authorities to alter or increase their efforts so as to bring them more into line with the needs of children and young persons.

The district teams must devise natural routines for co-operation with social services, schools and primary care and also with the State consultancy organization, social insurance offices, and the public Employment Service.

Social services, responsible as they are for all persons with handicap, have to provide relief assistance (assistance with care and supervision) for families with handicapped children, young persons and adults. Relief assistance must be individually adapted, regularly available, and of high quality. In very special situations, a form of assistance with care and supervision by means of a personal attendant attached to the individual with a handicap and not to a particular activity is recommended.

The County Council habilitation committees offer short-term care for children, young persons and adults with handicap, both in short-term homes with the same qualitative standards as group homes, and in relief families (for children and young persons).

The great majority of children and young persons, including many who are severely handicapped, live in their parental homes or in family homes. These forms of support will enable more children and young persons with handicaps to grow up in their families or in other private homes.

Group homes will during a five year period gradually supercede nursing homes, certain lodging houses and boarding homes. Special qualitative requirements for group homes are as follows: Group homes must be located in ordinary housing settlements and must constitute a permanent home for their residents. The number of children or young persons living in a group home ought not to exceed four.

Pre-school education, as in the case of all other children, serves both social and educational purposes. Children with handicap need to participate in a social community for their development. A further reason for pre-school programs is that parents need a break from the task of caring for their children.

Experience has shown that leisure activities at their best can offer a community experience which does justice to the principles of normalization and integration. Persons with handicap have more need than others for special measures giving them access to recreational and cultural amenities. This fact has been observed both by public authorities and by voluntary organizations, but many children, young persons and adults with handicap are still excluded.

Special arrangements must be made to provide support and services for immigrant families. Cultural background does a great deal to influence the way in which people appraise their needs of support, service and care. Cultural differences of approach to handicaps and the situation of handicapped persons should be dealt within the basic and subsequent training of the personnel providing initial information, parental education, crisis therapy, and other support.

Financial Support

A care allowance is available to families who have a child with disability who needs extra care. This is conditional on the child living at home and being under 16. Depending on how much extra care the child needs and/or how much extra expense is incurred because of his or her disability families can obtain a full or half care allowance. Part of this allowance is tax-free compensation for the extra expense in which the disability involves the family. Some counties also give a monthly home care grant for a child with mental retardation. The age limit for parental leave of absence for temporary child nursing has been raised to 16 years, since certain handicapped youngsters over the age of 12 may be incapable of looking after themselves at home when they are ill.

Families with children are eligible for a national-municipal housing allowance. The size of this allowance depends on income and housing costs. In some municipalities families with a disabled child can apply for a munici-

pal housing supplement for disabled persons (KBH for short). KBH is meant to enable families to choose a home suiting their child's special needs without incurring extra expense.

If a home needs to be modified on account of the child's disability, families can receive a home adjustment grant. This is a State grant and is not subject to a means test. It can be used, for example, to pay for a ramp, to remove door sills, and so on.

If the child's disability makes it impossible to travel in a normal way, families can apply for a travel assistance permit. This provides travel by taxi or special vehicle. An experimental scheme of national transport assistance for leisure journeys by train, boat, air, special vehicle or taxi has been in operation since 1980. Persons prevented by their disability from undertaking long journeys alone can apply for this form of transport assistance.

All County Councils have one or more technical aids centres where technical aids are tested and distributed. Most technical aids are free of charge. Certain disposable articles, e.g. napkins, syringes and bandages, can also be free of charge.

Experiences From The County of Stockholm

Stockholm County is the biggest county with one and a half million inhabitants and an area about 6,500 square kilometres. Everyone living in the region contributes through their taxes 14.5 per cent of their annual income to the cost of the County Council's activities. Of the total budget 7 per cent goes to the care committee, which serves a population of about 5,000 in all ages with mental retardation and to 1,700 children with physical impairments.

During 1975 an inventory was made of all the 5,000 persons with mental retardation and their needs for the coming period of ten years. The needs were related to the goals of normalization and integration. The following subdivided goals were set up by the County Council for the children:

Living in the home of the parents or other private homes should be given special support.

Preventive measures and family support in the form of home care should be given high priority. The children and their families should get immediate support and help with as little interference as possible.

The goal of the 10 year plan (1977-1987) was to increase from 62 per cent to 76 per cent children living in a family. The core of the support system is the district team and respite care.

From January 1986, the County has co-ordinated the training and care of handicapped children. Teams which earlier had worked only with physically disabled or mentally retarded have been brought together. The new teams also serve families with a deaf or blind child. Nine hundred are deaf or hearing impaired and 250 blind or with defective vision.

The other base in the support system is respite care. Every district has a short term home accommodating four or five children at the same time. Every family has the right to use the short term home a maximum of a week per month. This form of support can be combined with relief from the municipality, a person coming to the home a certain number of hours every week.

The results of the changing service system are reflected in the fact that 83 per cent of children (age 0-16) now live with their family (compared with 62 per cent in 1977). Nowadays, 90 per cent of pre-school children live with their family compared with 75 per cent in 1977. Only three children under the age of seven live in group homes. About 10 per cent live in foster homes.

The development has been similar in the rest of the country. In the beginning of the 1970s, about 2,500 children with mental retardation lived in institutions in Sweden. The 1968 Act underlined the principle of normalization. As a result the Counties started to build up different kinds of family support systems to avoid institutionalization of children. In 1968 there were only 400 children (0-18) living in institutions. Seven Counties did not have any children at all in institutions. Out of the four hundred less than 20 were under the age of seven and more than 200 were over the age of 16.

How Has Deinstitutionalization Affected the Families?

Families with children ages 11-14 were interviewed and all of the families (n = 300) who had children living at home in these ages were surveyed. This age group was chosen because they grew up after the 1968 law had gone into effect.

Forty per cent were girls and 60 per cent boys. According to the judgements of the parents, 35 per cent had mild, 49 per cent had moderate, and 16 per cent had severe mental retardation. The lower number of mildly mentally retarded has to do with the fact that the "No Answer" responses were greater in this group. Several of the parents thought that the study did not have anything to do with them since their children were not mentally retarded. The parents with mildly mentally retarded children usually refuse to acknowledge that the child has a retardation, and because of this the parents often place themselves outside the services that society can give. This is, incidentally, an important part of the results of this research. Probably the parents also have the tendency to class some of the mildly mentally retarded children as moderately mentally retarded.

To sum up, while the children in the study were mentally retarded, and often multihandicapped, the parents kept them at home. This despite the fact that the parents have been offered other alternatives, e.g. group homes for their children.

Approximately two-thirds of the mentally retarded children live in a family with an adult couple who live together; nearly one-third of this group do not live as such. This is considerably more than is normal in Sweden; about 10 per cent of children ages 7 to 12 in Sweden live with one parent. The data give no

indication as to whether the parents' willingness to separate increases with the severity of the handicap; on the contrary, it seems rather to be a result as to whether there exists a handicap or not.

Overall, 23 per cent of the parents think that siblings of the handicapped child are daily confronted with unreasonable demands. The number is about 30 per cent among the parents with severely retarded children. About 60 per cent of the parents have changed their values and about 40 per cent believe that siblings become more tolerant for having a handicapped brother/sister.

Close to a quarter of the families have acquired a different circle of friends. Only 10 per cent believe that their religion has been a support. Twenty-five per cent agree completely with the statement, "A child's handicap often guides the parents to a special career field or changes the direction of their work."

A handicapped child who lives at home influences the family in a number of ways. Several parents, after a divorce, live alone with the child. Their values change.

Approximately 90 per cent of the children took part in classroom education in special classes. The rest of them had special education at home or some other special arrangement. At the end of the school day, 50 per cent of the children go to a municipal recreation centre or day-care mother. Forty per cent are in the homes of their parents. The children (64 per cent), according to their parents, have considerably fewer friends as compared to what non-handicapped children have.

About a third of the families have no relative or friend who can take their place in case of need. The parents have a right to relief through municipal domestic help in the home, short-term family, or short-term home. A careful examination of the data does not show any connection between the households which use these services and their yearly income, although it is often reported that it is the well-favoured who take advantage of these opportunities.

The demand for increased services increases with the degree of mental retardation. Seventy-six per cent of those with severely mentally retarded children think that the possibilities for relief are not enough, compared to 55 per cent of those with moderately mentally retarded children and 33 per cent of those with mildly mentally retarded children.

Despite the fact that there exists a single responsible authority, 33 per cent of the parents think that it is difficult to get information about rights and services.

The great majority of the families, nearly 90 per cent, are satisfied with their living conditions. This is similar to the overall national average.

The tendency to change housing area is just as great among families of the handicapped as the comparative data for the nation as a whole. Few citizens of Sweden today have any special permanent "roots" in the meaning that one has access to old friends and acquaintances or relatives among the neighbours. Only approximately one-third of the population has lived as long

as ten years in the same place. This can be a disadvantage for the handicapped child. The neighbours, shop personnel, and other groups, who possibly could be thought of to establish contact with and be a helping hand with the child, know neither the child nor the parents.

Nearly all fathers work full time or more than half-time. About 45 per cent of the mothers of the severely retarded children and more than 20 per cent of the mothers of the moderately retarded children do not work outside of the home. Forty to fifty per cent of the employed mothers work in care-oriented careers (registered nurse, doctor, day nurse, pre-school teacher, etc.). This compares with a national total of twenty to thirty per cent. For the men, it appears to be about average for the country.

Certain other differences between men and women are clear. Thirty-four per cent of the women and 8 per cent of the men have reduced work hours. Nineteen per cent of the mothers, compared with 1 per cent of the fathers, have given up work. Similar differences appear in terms of having to take off from work in order to care and attend to the handicapped child.

	Men	**Women**
Each week	4%	3%
Several times per month	5%	6%
Some times per month	13%	23%
A couple of times per year	35%	31%
Never or almost never	44%	37%

Most of the children still need practical help with eating, dressing themselves, and hygiene. Twenty-seven per cent need very much help and just as many are able to take care of themselves. Thirty per cent of the families spend 3 to 4 hours extra per day on the child; 25 per cent 5 hours extra. Parents of mildly retarded children spend at least one hour per day extra, whereas the parents of severely mentally retarded children spend about 5 hours extra per day.

There are indications that the parents of children with physical impairments often suffer from tiredness, as compared to others, that psychotic children can contribute to feelings of listlessness, low-spiritedness, and restlessness. The physical strains of having a severely mentally retarded child is evident. Forty-eight per cent of the parents of the severely retarded children almost never get to sleep undisturbed a complete night.

The picture of a lower quality of life in terms of recreation and leisure time becomes more clear with the increasing degree of retardation. Fifty-six per cent of the parents think that families with mentally retarded children are more isolated than other families with children (76 per cent among those with a severely mentally retarded child). Approximately 25 per cent think that their

friends think it is difficult to be together with the handicapped child (38 per cent among those with a severely mentally retarded child).

Scarcely 25 per cent of the children are aware of their handicap and an additional 30 per cent are beginning to be aware of it, according to their parents. Only 3 per cent of the mildly mentally retarded are aware, according to the parents. Approximately every fourth parent thinks that it is difficult to talk with the child about his or her handicap. Eighteen per cent of the parents agree completely with the statement, "A handicap shakes the parents' feeling of self-confidence."

Families with a mentally retarded child are exposed to more stress as compared with other families. Wikler has given an account of the different kinds of chronic stress, like stigmatized social relations, prolonged time of care, lack of information, sorrow. In addition, she has tried to map out if it is possible to predict certain critical periods during the life cycle. Five of these are connected to developmental milestones, such as when the child normally would begin to walk, begin to talk, begin school, beginning of puberty, and coming of age day. The other five are connected to events that are only experienced by the parents of a handicapped child, such as discussions about placing the child outside of the home, special health problems, and discussions of institutionalization.

For the group with severe mentally retarded children the strains steadily increase from 4 to 5 years of age. In the families with mildly mentally retarded children there is a peak around the start of school and then the curve goes down.

The increased stress in families with children who have severe mental retardation is mirrored also in the parents' judgement of when the child should move away from home. In families with mildly mentally retarded children there are none who think that the child should move before the age of 18, while 20 per cent of those with severe mentally retarded children think that the child should move away from home sooner. The parents do not believe that they will take upon themselves a life-long care of their children.

Reflections

What is the next step? Will we be able to shut down all, or almost all, institutions for children? To enable us to take further steps in that direction there will have to be more support to the families in terms of relief in care, leisure activities, psychological and social support.

The aim is that these children will grow up with their families. The graph of strain that faces parents of severely handicapped children—parents in this context in reality often meaning mothers—increases every year. In families with moderately mentally retarded children the strain starts to increase at the time the children become 9 to 10 years old.

The society has by its normative power contributed to the fact that more and more families decide to keep their children at home. Increasing public care for mentally retarded children and increased support to the families has facilitated the process.

If cuts in public services, such as have occurred in almost all industrialized countries, should mean diminishing support to these families, it would be treachery to normalization. Then the next generation of parents would not dare to take the responsibility for having their children at home.

FAMILY SUPPORT IN CANADA— TRENDS AND CHALLENGES

Bruce E. Kappel

In Canada, the family is recognized as a cornerstone of society. We believe that children belong in families, and benefit from the affection, moral and material security they provide. Provincial legislation, speeches by government leaders, and provincial policy papers underscore this belief time and again. The language of legislation in Alberta is but one example—"The family is the basic unit of society and its well-being should be supported and preserved," and "The family is responsible for the care and supervision of its children and every child should have an opportunity to be a wanted and valued member of a family."

For many years, however, the basic and unfortunate reality for many families has been that their well-being has gone unsupported and unpreserved. For many children, there has not been the opportunity to be a wanted and valued member of a family.

For decades, the dark side of the Canadian reality has been that there is precious little that has stood between a family in need of support and institutionalization as the only option. Families have been stripped of their power by professionals and agencies that made decisions for them. Families were encouraged to rely on special services which took the place of the support available from family, friends, neighbours, associates and generic services. Families were denied support, yet encouraged to place their children in services which received support. And most powerfully, professionals often gave families little sense of hope, little sense of what is possible, and little to fight with.

The bright side of the Canadian reality is that much is changing. This change is partially reflected in a number of articles and publications which have come out of the G. Allan Roeher Institute (formerly the National Institute on Mental Retardation), a bibliography of which is presented at the end of this paper. In this paper, I would like to highlight some of the encouraging trends which appear firmly established, at least in parts of the country.

Linking Family Support and Deinstitutionalization

Across Canada, there are increasing commitments by provincial governments to two powerful approaches:

(i) supporting families of children who are at risk of institutionalization, and
(ii) supporting children who have been institutionalized to return to their families or alternative family settings.

These commitments have been strongest in two provinces in Atlantic Canada—New Brunswick, and Newfoundland and Labrador. Historically, both provinces have been resource-poor in terms of human services, and experienced sustained periods of economic hardship. They are clearly not among the best or better off provinces. They have small populations (600-800,000) and are largely rural in nature. They are both excellent examples of governments and communities working on behalf of children and families.

In **Newfoundland** (Browne, et. al. 1986; Kappel and Cawthorpe, 1983; "Respite Services..." 1982), the Department of Social Services has developed an array of family support services over the last decade—in-home support, respite services, child and behaviour management programs, a special child welfare allowance, and so on. The Newfoundland Association for Community Living (formerly, the Canadian Association for the Mentally Retarded—Newfoundland and Labrador Division) has been active in stimulating the development of these programs, and itself working closely with communities and families to develop local networks of formal and informal support. The results have been impressive—there are no children in institutions in the province; of the two former children's institutions, one has been closed, and the second is in the process of closing; and there are no children living in group residential situations.

The government and the Association have radically altered the "supply side" of human services. The emphasis is on supporting families and supporting children to live in families. There have also been tremendous changes in the "demand side". Through the work of the Association and the government staff providing in-home support, families have developed a new sense of what is possible—the full, meaningful, and lifelong integration of their children in the life of the community.

In **New Brunswick,** the W. F. Roberts Hospital School, the single children's institution in the province, has been recently closed (Brewer, 1986; McWhorter, 1986). According to a recent presentation by a New Brunswick government official, 50% of the children are now living with their parents, 25% are living in foster arrangements, and 25% are living in group situations. The Government also committed itself to develop community-based deinsti-

tutionalization effort. The results—the 135 children from the institution are in the community, and an additional 800 children and families are also receiving services.

The core services to children (and by extension, to families) are as follows: an interdisciplinary assessment and case planning process; service coordination; respite care (there are 75 respite foster care homes in the province); family support; residential services (with a long term goal of phasing out group homes for children); rehabilitation services; educational assessment and individual education planning; and early intervention.

Again, the provincial association (the New Brunswick Association for Community Living) played an active role in advocating for and shaping public policy.

Four core features of these approaches have been:

- long term planning which saw the benefit of supporting families in the first place, for the sake of the children and families, but also to avoid institutionalization;
- the reallocation of institutional resources to services that make more sense;
- a government commitment to removing institutions from the lives of children so that the capabilities of communities to sustain and support their fellow members could be developed;
- consistent involvement by the provincial association in advocating for and shaping public policy for institutional closure and family support.

Empowering Families

In a number of communities and some provinces, the emphasis has shifted from usurping the power and responsibilities of families to enhancing and supporting that power and responsibility. This has taken a number of forms:

- decision making power: ensuring that families have an active and decisive role in determining what their sons and daughters need, and how those needs should be met;
- spending power: based on identified needs, putting funds at the disposal of families for them to purchase what they need;
- power from professionals: teaching skills to parents, putting the skills of professionals at the disposal of parents;
- power and support from other parents: parents developing their own power base with other parents.

By and large, families in Canada depend on the discretion of agencies and governments as to what is offered, when and to whom. Despite the fact that many services have developed in the first place because of the united efforts of families (usually in the context of local associations), individual families have had little power in determining the design, development and

delivery of services for their sons and daughters. By and large, they have had to fit into the services, rather than have the service fit them.

In a number of notable exceptions this is changing—families are being empowered to make and monitor decisions on their own behalf. This has been particularly the case when governments have engaged in large scale deinstitutionalization efforts and have included some form of case management or individual service planning and coordination in the process. The respectful inclusion of families in the process has been less than ideal, but in some cases, exceptional efforts have been taken to inform parents of the quality options (including assisting them to visit quality programs elsewhere), and respect their wishes for the future.

This process of family empowerment is perhaps best illustrated in the Community Living Society of Vancouver, British Columbia where a group of parents (the Woodlands Parents Group) developed an agency shaped by parents and dedicated to taking the lead from the individuals and families it serves (NIMR, 1982; Rioux and Crawford, 1983). Other efforts across Canada, which are far less empowering, yet nevertheless recognize the family's role in decision making, include individual education plans, annual reviews of the status of children in institutions, individual planning processes associated with special needs funding.

In a number of provinces, families have also been empowered through the granting of funds directly to families, or associated with individual plans developed with families. Such funds have enabled families to purchase goods and services ranging from apparently mundane things as babysitters to the joint efforts of a collection of families to mount a new service in their community.

Increasingly, professionals have recognized that they can be of best service when they give their skills and knowledge to families, thus involving them in their children's growth and development, and the building of the future. There are growing numbers of in-home support programs to the families of young children which often focus on infant stimulation, child management, and early intervention approaches, but also extend into advocacy and future planning. At their best, such programs have nurtured the development of communities of parents who are demanding more from the system and who see integration as a matter of right. At their best, such programs also extend the power of families because the family support workers work on the family's behalf in gaining access to generic services in the community, and where needed, adapting those services. As is often the case, some of the better programs have emerged in rural and remote areas. (Browne, et. al., 1986; Bell and Gosselin, 1983; Coshan, 1982; Melberg, 1986)

Perhaps the most powerful trend is in the area of families working together for mutual support and social change. The families often have children with mental handicaps, but not always. Parent support groups,

Extend-a-Family, Pilot Parents, Integration Action groups, and other groups of parents are steadily developing across the country, often with little or no support from funding bodies. Whether it be on an individual level or in terms of social change, the common theme is that parents have commitment, knowledge, power, and expertise, all of which can be shared and used to common advantage. The common advantage ranges from relief and respite to the integration of a school and classroom, from sharing frustrations and knowing that others have travelled the same road to stopping the construction of an institution. (Coshan, 1982; Forest, 1985; Galati, 1984; Gravel and Caron, 1984; NIMR, 1986; "Parents' Study Group", 1982; Pivato and Chomicki, 1986; Ruff, 1986; Sharratt, 1982; "Outreach", 1982)

A Commitment to Integration and the Power of Natural Supports

Increasing numbers of families are being supported and preserved because of a simple, but often ignored, reality—the support that comes from more and more non-handicapped people being involved in their sons' and daughters' lives. Integration, at the level of social and physical association with others, has meant that in increasing numbers of pre-school programs, school classrooms, workplaces, neighbourhoods, and community places people with handicaps are developing friendships with people who are ready, willing and able to stand beside them and up for them. Citizen advocacy programs, church groups (Preheim-Bartel and Neufeldt, 1986) cooperative housing organizations, and so on are taking an active role in encouraging "neighbourly, fellow citizen" approaches to support.

The Prairie Housing Cooperative (Kappel and Wetherow, 1986) was intentionally established to facilitate neighbourly support among handicapped and non-handicapped citizens. A number of local associations are establishing Associate Family programs (Lynes, 1983) where families are recruited to provide varying amounts of support to a family with a handicapped child—ranging from occasional respite to the child living with the associate family and spending time with the natural family.

Families whose children are totally integrated into regular classrooms are discovering that the resulting friendships have a powerful and positive effect on their lives and learning (Ruttimann and Forest, 1986).

New Visions

These and similar efforts across Canada are having a profound impact on the vision families have of the future. That vision sustains them in their struggles for appropriate support and services.

That vision is now aided and abetted by, among other things, a new series of publications from the G. Allan Roeher Institute—Making a Difference: What communities can do to prevent mental handicap and promote lives of quality (NIMR, 1986). In five volumes, the series addresses issues

facing the lives of Canadians with mental handicaps, what some communities have done to address those issues, and what we can all do in the future.

And finally, that vision has been expressed in a series of objectives set by the Canadian Association for Community Living (1986) for the year 1992:

1. By 1992 all children will have a meaningful family life.
2. By 1992 all children will go to school together with other children in the neighborhood, and get an age-appropriate program to match their needs in regular school classes.
3. By 1992 everyone leaving high school will have the opportunity to get and keep meaningful work in integrated settings.
4. The number of people in sheltered workshops will decrease by ten percent per year from the 1986 level as a result of people becoming employed.
5. The use of tax dollars to meet people's needs will be decided between the person who needs help and the provincial government.
6. By 1987 admissions to institutions will stop and evacuation will proceed at ten percent per year based on 1986 populations.
7. By 1992, a personal support network, securing the indivdual's place among friends and family, will be a commonplace approach to assuring one's future.

These seven objectives have been identified by the CACL as feasible, though ambitious steps toward the vision we as Canadians share. These objectives will give direction to the Association's leaders and staff in making decisions and allocating resources.

Much has been accomplished. A formidable challenge remains, but we at least now have a wealth of personal and community experience with what the future can and should look like.

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